

InterPARES
Trust



InterPARES Report

Team Europe EU19 project 2014-15: A
Research Report into Open Government Data in
NHS England

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Abstract

Purpose: The purpose of this report is to consider the requirements for operating effective and trusted proactive release of information for re-use within England's health sector, in the context of new obligations on NHS England towards Open Government Data. This report asks the following research questions:

What policies, guidance and advice exist for operating effective and trusted proactive release of information within NHS England?

What is the role of the Records Manager in an Open Government Data environment in NHS England?

Design/methodology/approach: This report uses semi-structured qualitative interviews as the main approach; three of these interviews were conducted face-to-face, and one was conducted via email. The qualitative data collected is analysed and compared to wider discussions in the relevant literature. A review of the relevant literature underpins the whole report, especially Chapters One and Three. The research was carried out over the period, April to August 2015 by researcher and Masters student, Emma Harrison, guided by Co-Is, Dr Andrew Flinn and Professor Elizabeth Shepherd, all at UCL, Department of Information Studies.

Findings: Open Government Data in the health sector is in its infancy, with many still trying to form answers to the question, "What does Open Government Data mean for the health sector?". In these early stages of policy development, the Open Government Data agenda in the NHS is worryingly dependent on a small number of central figures, or champions, who are actively pushing forward the policy, producing a fragile system that may be in risk of collapsing completely. The policy being pushed forward by the Open Government Data champions in NHS England is not a physical, tangible policy, but is more complex, an agenda that includes the difficult challenge of educating others as to the

meaning and purpose of Open Government Data, and also includes the challenge of embedding the agenda across all work practices in NHS England.

There does not currently seem to be a natural synergy between Records Management and Open Government Data in the NHS; whilst a closer relationship between the two would certainly support the development of Open Government Data, a closer relationship would need to be actively developed. Developing this closer relationship, however, is challenging, complicated by the fixed connotations associated with Records Management in the NHS, and the extinction of the “traditional” Records Manager in NHS England, subsumed by Information Governance.

Research limitations/implications: Only a small number of interviews were conducted, therefore this research is limited by difficulties in generalising the findings. The findings are only relevant to NHS England and cannot be generalised to include Scotland, Wales and/or Northern Ireland, which are all separate organisational entities.

Originality/value: This report adds value to current research and discussions in the developing area of Open Government Data, especially so in writing from a recordkeeping perspective and within the context of England’s health sector. Expert and specialist knowledge collected through interviews from senior positions at TNA, NHS England, and HSCIC also adds value to this report. The value of this report is also in the intellectual interrogation of not only Open Government Data as a concept, but also of the sister concepts, accountability, transparency, and governance.

Keywords: Open Government Data, Open Government, Recordkeeping, Records Manager, Records Management, Government, Public, National Health Service, NHS, Health Sector, Policy, England, Guidance, Legislation, Transparency, Information Governance.

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List of abbreviations and acronyms

ASD Archive Sector Development

DEFRA Department for Environment, Food & Rural Affairs

DH Department of Health

DP Data Protection

DPA Data Protection Act

FOI Freedom of Information

FOIA Freedom of Information Act

HDP Head of Data Policy

HSCIC Health and Social Care Information Centre

IG Information Governance

IGT Information Governance Toolkit

IG SoC Information Governance Statement of Compliance

NHS National Health Service

NHS RM Code NHS Records Management Code

PRA Public Records Act

PSI Public-Sector Information

RTR Record Transfer Reports

SDSPS Senior Data Sharing and Privacy Specialist

TNA The National Archives

Chapter One

Introduction

1.1 Introduction

‘The future will be Open’, according to Cabinet Minister Francis Maude’s foreword to the 2012 *Open Data White Paper*, a paper which posits ‘a truly transparent society’ as an ideal towards which the government is working.¹ Openness and transparency are principles categorically engrained into today’s society. Philosopher Onora O’Neill considers this move towards openness and transparency in a BBC Radio Four lecture:

Openness and transparency are now possible on a scale of which past ages could barely dream. We are flooded with information about government departments and government policies, about public opinion and public debate, about school, hospital and university league tables [...] [a]t the click of a mouse.²

Considering the frequency with which openness is referred to in today’s society, it is timely to consider Open Government Data. This report will present a conceptual and contextual introductory chapter; presented in Chapter One is a definition of Open Government Data, alongside definitions of relevant sister terms, *transparency*, *accountability* and *governance*. Chapter One will also present a contextual introduction to NHS England, the focus of this study on Open Government Data, as well as a contextual introduction to relevant legislation, including the *FOIA*, *DPA*, and the *Health and Social Care Act*. Chapter Two outlines and justifies the methodology used in this report, whilst Chapter Three analyses and discusses the data collected from a number of interviews; the aim of the interviews was to gain expert knowledge regarding policies and implementation of Open Government Data in NHS England. Chapter Four offers a conclusion and, overall, this report will demonstrate that the Open Government Data agenda is in its infancy in NHS England, as it also is elsewhere in the UK; whilst credible steps are being taken to

¹ *HM Government Open Data White Paper: Unleashing the Potential* <http://data.gov.uk/sites/default/files/Open_data_White_Paper.pdf> [accessed 9 June 2015], p. 6, p. 45.

² Onora O’Neill, ‘Lecture 4: Trust and Transparency’, *BBC Radio 4: Reith Lectures 2002* <<http://www.bbc.co.uk/print/radio4/reith2002/lecture1.shtml?print>> [accessed 12 June 2015].

further develop the agenda, there are a number of complex challenges with Open Government Data in NHS England that may inhibit any real, progressive developments.

1.2 Open Government Data

What is Open Government Data? A seemingly simple question, but this question is fraught with complexity and contention. This report purposefully adopts the term *Open Government Data*, defined and used throughout this report as *the release of information by public sector bodies for re-use, released with the aim of achieving a number of, sometimes rather different, benefits*. Open Government Data, in this report, is specific to the UK's public sector, for it is posited on the belief that taxpayers should be granted information regarding taxpayer-funded services, to re-use with minimal restrictions. Open Government Data is not specifically related to the health sector; the HSCIC aptly describes Open Data and the transparency agenda as 'a pan-government initiative'.³ Jo Bates approaches a definition of Open Government Data from a similar perspective as the one presented in this report:

Open Government Data is an information policy which provides a particular framework for governing the *re-use* by third parties of datasets that are produced by public institutions. [...] The proposal for Open Government Data argues that non-personal data that is produced by public bodies should be opened for all to re-use, free of charge, and without discrimination.⁴

Rather than referring to datasets specifically, as Bates does, this report promotes a wider and less prescriptive definition of Open Government Data by adopting the term *information*, thus not dictating any specific format. Unless quoting from elsewhere, this

³ HSCIC, 'Supporting Transparency and Open Data', *HSCIC* <<http://www.hscic.gov.uk/transparency>> [accessed 12 June 2015].

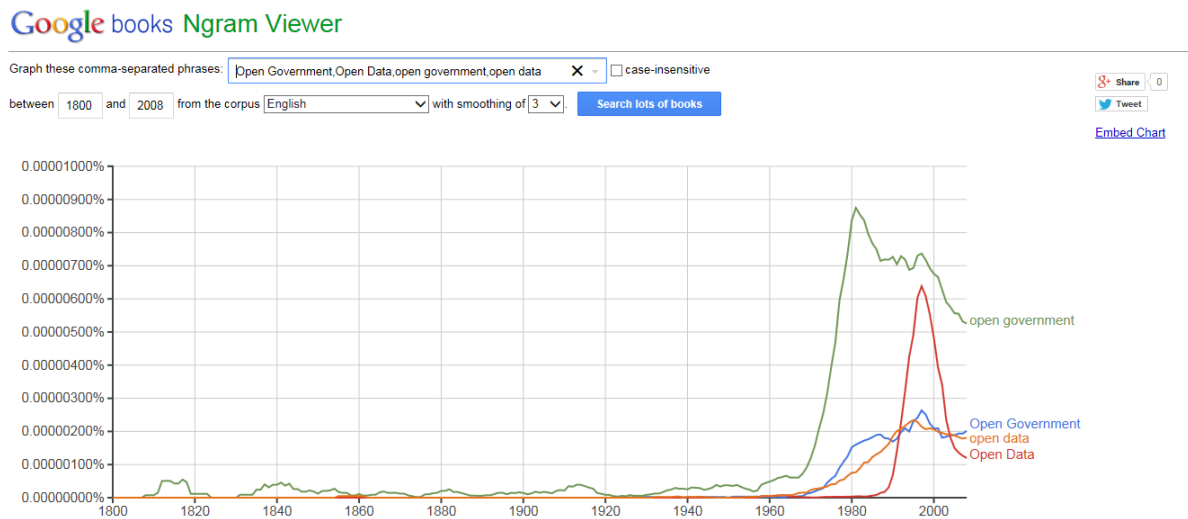
⁴ Jo Bates, 'The Strategic Importance of Information Policy for the Contemporary Neoliberal State: The Case of Open Government Data in the United Kingdom', *Government Information Quarterly*, 31 (2014), 388-395 (p. 390).

report capitalises the term Open Government Data, using it as a noun, for although it is not a tangible ‘thing’, it is an idea (*OED*).

There is an acknowledged lack of intellectual consistency regarding definitions in the discourse on Open Government Data, Open Data, and Open Government. For example, Harlan Yu and David G. Robinson strongly believe that the term Open Government Data is ‘deeply ambiguous’, a term that blurs the lines between Open Data and Open Government, thus they advocate a framework to ‘separate the politics of open government from the technologies of open data’.⁵ Yu and Robinson consider the ‘conceptual histories’ of the two terms, drawing on the origins of Open Government in a post-Second World War context, used then as ‘synonym for public accountability’ (p. 184). Open Data, they argue, developed only in the latter half of the twentieth century, with the adjective *Open* acting as ‘a powerful, compact prefix that captures information technologies’ transformative potential to enhance the availability and usefulness of information’ (p. 187). Certainly, the claims regarding the conceptual histories are reflected in a Google Ngram Viewer (Figure 1), whereby peaks in the use of the term Open Data occur later than peaks in the term Open Government. The use of the Google Ngram Viewer tool, however, is limited as the computer-generated results inevitably include non-relevant references or neglect relevant references, resulting from the computer’s inability to decode context. Nevertheless, the Google Ngram Viewer can be used cautiously to provide a general indication of the changing use of certain phrases over time.

⁵ Harlan Yu and David G. Robinson, ‘The New Ambiguity of “Open Government”’, *UCLA Law Review Discourse*, 59 (2012), 178-208 (p. 181). All subsequent references in this chapter are given in parentheses immediately following the reference.

Figure 1⁶
Google Ngram Viewer of the phrases Open Government and Open Data



Distinctions between Open Data and Open Government have been adopted elsewhere,⁷ but the claims made by Yu and Robinson, that a merger of the two terms means ‘the phrase “open government” no longer has the clarity it once had’ (p. 202), ignores an abundance of intellectual history discussing problems in defining the term Open Government. Open Government, as a phrase, has never possessed clarity, and therefore cannot lose it. Writing in 1985, Colin Bennett, a political scientist, claimed that the Open Government debate is ‘neither coherent nor focused’, with a number of different terms used synonymously, overall resulting in ‘a lack of conceptual and theoretical coherency’.⁸ Furthermore, Richard A. Chapman and Michael Hunt also considered the overlapping use of definitions in Open Government discourse, demonstrating a history of “fuzzy” terminology.⁹

⁶ Google Ngram Viewer <<https://books.google.com/ngrams/>> [accessed 12 June 2015].

⁷ See, for example: Ben Worthy, *David Cameron’s Transparency Revolution* <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2361428> [accessed 12 June 2015].

⁸ Colin Bennett, ‘From the Dark to the Light: The Open Government Debate in Britain’, *Journal of Public Policy*, 5:2 (1985), 187-213 (pp. 188-189).

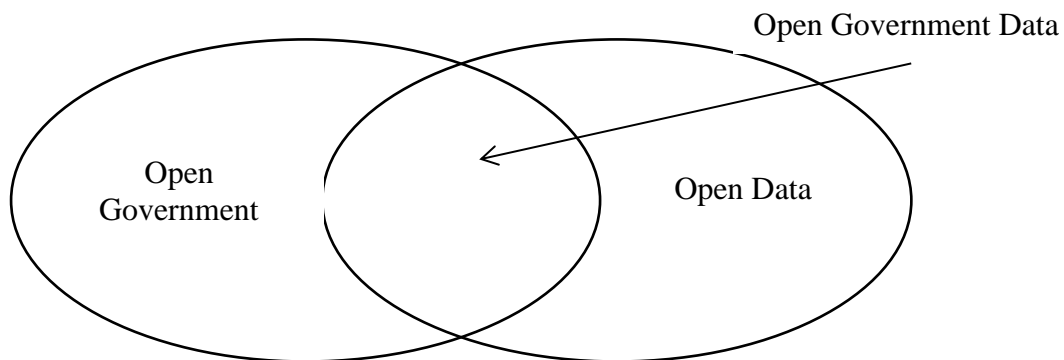
⁹ Richard A. Chapman and Michael Hunt, *Open Government in a Theoretical and Practical Context* (Aldershot: Ashgate, 2006), p. 3.

Yu and Robinson argue that the usually ambiguous term Open Government Data ‘may sometimes be beneficial’ (p. 182), and it is proposed here that the term is indeed beneficial when considering Open Government Data from the perspective of the NHS. A fuzzy boundary, or a fuzzy overlap, is embraced. The NHS is a taxpayer-funded service that is, consequently, fundamentally political, in the simple sense that political means, ‘of, belonging to, or concerned with the form, organization, and administration of a state’ (*OED*). John Appleby, Chief Economist, argued in a 2013 blog post that ‘[t]o say the NHS is political is to state the obvious’, further arguing that ‘the nature and origin of its birth, [and] the way it is funded’ are some of the ways in which the NHS is political.¹⁰ Whilst fundamentally political the NHS is simultaneously a healthcare service that is harnessing new technologies to release information for re-use by third parties, with a number of different benefits in mind, including but not limited to, driving up standards of care and increasing transparency to gain, or perhaps to re-gain after a number of scandals have hit the news headlines in recent years, public trust. Transparency and technology are often seen, not as separate, but as mutually dependent in the health sector; for example, the *Personalised Health and Care 2020* policy paper highlights a support of transparency through website initiatives such as *NHS Choices*, by ‘opening data to public scrutiny and driving improved performance’.¹¹ The politics of Open Government and the technology of Open Data cannot be so neatly divorced in the NHS; they do not, and cannot, exist separately with such rigid, divisional boundaries. Open Government Data in NHS England, therefore, takes on the definition as given by Yu and Robinson: ‘governmental data that is both politically sensitive and computer provided’ (p. 182), depicted in Figure 2.

¹⁰ John Appleby, ‘Politics and Satisfaction with the NHS’, *The King’s Fund* <<http://www.kingsfund.org.uk/blog/2013/04/politics-and-satisfaction-nhs>> [accessed 20 June 2015].

¹¹ *National Information Board Health Personalised Health and Care 2020* <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf> [accessed 9 June 2015].

Figure 2
Author's own Schematic Representation of the phrases Open Government Data, Open Government and Open Data



1.3 Transparency, Accountability, and Governance

As a concept, Open Government Data does not stand in isolation; Open Government Data is invariably mentioned alongside other key concepts, including *transparency, accountability and governance*. In defining the term Open Government Data, it is also necessary to define these sister concepts, in turn.

All three of these sister concepts are Westernised ideals, heralded by Western cultures as ethically “correct”, or ethically “moral”. Transparency, accountability and governance are frequently posited as the basis to a truly democratic society. For example, Chapman and Hunt consider the overlapping use of the terms transparency, accountability, and democracy in Open Government discourse. Showing the interweaving and complex relationship between these terms, the writers claim that ‘a variation on the term “open government” is that of “transparency” a term which also carries an association with the prevention of corruption. Indeed, for many countries a commitment to transparency forms an essential part of the process of accountability’.¹² Furthermore, Chapman and Hunt even claim that ‘accountability is the most important aspect of democracy’;¹³ such a categorical

¹² Chapman and Hunt, *Open Government*, p. 3.

¹³ Chapman and Hunt, *Open Government*, p. 140.

argument veers dangerously close to K. G. Robertson's 'normative approach' to Open Government, an approach which Robertson criticises: 'the dominant argument has been that the values of a modern liberal democratic state require public access to government information, with secrecy being seen as a residue of a pre-modern, elitist and undemocratic culture'.¹⁴ This report cautiously avoids simply placing openness on a pedestal of properness to herald it as ethically correct, whilst also condemning secrecy as morally corrupt. Drawing on the work of Anthony Giddens, Robertson further argues that surveillance theory, including Michael Foucault's panopticism whereby 'perfect disciplinary apparatus would make it possible for a single gaze to see everything', 'is a key feature of the nation-state', even concurring with Giddens's argument that 'the state could not exist' 'without the capacity to code and store information'.¹⁵ It is important to carefully consider the definitions of the terms so frequently associated with Open Government Data, but, taking account of Robertson, the author refrains from assigning any moral judgements that would reduce the terms to mere binary oppositions of "good" or "bad".

1.3.1 Transparency

An *OED* definition of the term *transparency* fails to adequately capture the extent to which the term is used in Open Government Data discourse, including in England's health sector, merely defining it as 'the quality or condition of being transparent'.

Transparency is defined within an Open Government Data paradigm by the *Open Government Guide*:

In a well-functioning, democratic society citizens need to know what their government is doing. To do that, they must be able freely to access data and information and to analyse and share that information with other citizens.¹⁶

¹⁴ K. G. Robertson, *Secrecy and Open Government: Why Governments Want You to Know* (Basingstoke: Macmillan, 1999), p. 25.

¹⁵ Robertson, *Secrecy and Open Government*, p. 27.

¹⁶ Open Government Guide, *Open Government Data* <<http://www.opengovguide.com/topics/open-government-data/>> [accessed 24 June 2015].

Here, transparency is directly linked to democracy, problematically promoting Westernised ideals. As mentioned above, such an approach oversimplifies the concept by categorically promoting transparency as democratic, and therefore, perhaps less explicitly, promoting transparency as “correct” or “good”. Such a strict and rigid division is unhelpful and oversimplifies any discussions. O’Neill has discussed this unhelpful promotion of transparency as “good” or “right”, in strict opposition to secrecy which is often perceived as “bad” or “wrong”:

Transparency certainly destroys secrecy: but it may not limit the deception and deliberate misinformation that undermine relations of trust. [...] Transparency and openness may not be the unconditional goods that they are fashionably supposed to be.¹⁷

O’Neill substantiates her argument by claiming that there has been a growth in public distrust, despite openness and transparency being ‘avidly pursued’,¹⁸ though empirical evidence supporting the claim that public distrust has increased is lacking. There has, however, been discussions of a “post-it note culture” developing through a fear of disclosure, inhibiting transparency and highlighting O’Neill’s comments on ‘deception and deliberate misinformation’ [above]. In a 2011 blog article, Anne Walsh claimed that ‘evidence of a post-it note culture, where sensitive information is recorded on easily removable and undocumented sticky notes, exists already’.¹⁹

Though avoiding assigning moral judgements to the term transparency, this report is acutely aware that such moral judgements are often prescribed by others and by society as a whole, as the above discussion has demonstrated. Such moral prescriptions persist in

¹⁷ O’Neill, ‘Lecture 4: Trust and Transparency’, *BBC Radio 4: Reith Lectures 2002* <<http://www.bbc.co.uk/print/radio4/reith2002/lecture1.shtml?print>> [accessed 12 June 2015].

¹⁸ Ibid.

¹⁹ Anne Walsh, *The Coalition Government is Facing Criticism for its Failure to Keep the Transparency Agenda Moving Forward, but Lessons can be Learned by Looking to Canada* <http://eprints.lse.ac.uk/35436/1/blogs.lse.ac.uk-The_coalition_government_is_facing_criticism_for_its_failure_to_keep_the_transparency_agenda_moving_f.pdf> [last accessed 23 April 2015].

the Open Government Guide, where transparency is seen as a ‘huge potential benefit’ of Open Government Data.²⁰ Additionally, transparency is a central facet of NHS England’s organisational vision. For example, *NHS Choices*, a website that opens up performance data in NHS England, aims to simultaneously ‘support transparency and drive quality’.²¹ Sir Bruce Keogh, NHS England’s Medical Director, also comments on the role of the website in supporting accountability,²² demonstrating the overlapping nature of terms such as transparency and accountability, especially in Open Government Data discussions.

This report recognises that transparency, seen here as synonymous with visibility, is often seen as an ethically correct basis of a democratic society, although more complex discussions are arising with regards to transparency, seen, for example, in O’Neill’s work. Additionally, transparency is also often seen as a benefit of Open Government Data, as is accountability, discussed below. There are, however, increasing discussions as to whether the assumed benefits of Open Government Data, such as transparency, are actually being fulfilled, with a growing recognition that any benefits come not from releasing data, but come instead from the use of data: ‘Open Data on its own has little intrinsic value; the value is created by its use’.²³

1.3.2 Accountability

The *OED* defines *accountability* as:

[t]he quality of being accountable; liability to account for and answer one’s own conduct, performance of duties, etc. (in modern use often with regard to parliamentary, corporate, or financial liability to the public, shareholders, etc); responsibility.

²⁰ Open Government Guide, *Open Government Data* <<http://www.opengovguide.com/topics/open-government-data/>> [accessed 24 June 2015].

²¹ *NHS Choices* <<http://www.nhs.uk/Pages/HomePage.aspx>> [accessed 24 June 2015].

²² *Ibid.*

²³ Marijn Janssen, Yannis Charalabidis, and Anneke Zuiderwijk, ‘Benefits, Adoption Barriers and Myths of Open Data and Open Government’, *Information Systems Management*, 29 (2012), 258-268.

There appears to be a growing demand for those in power to be held to account; in 2011, David Cameron commented that ‘[i]nformation is power. It lets people hold the powerful to account [...]. In so many ways, information is a national asset, and it’s time it was shared’.²⁴ Cameron’s speech talks about accountability whilst simultaneously also talking about transparency and openness as achieved through technology, once again showing the overlapping nature of a number of terms in Open Government Data discourse.

The demand for accountability, however, is not as recent as one may assume it to be. Writing in 1985, but still relevant today, Bennett considered the demand for openness and accountability by highlighting instances such as the efforts by the *Sunday Times* to prevent publication of the now notorious thalidomide cases, and the questioning of circumstances relating to the ‘sinking of the *General Belgrano* during the Falklands War’.²⁵ Additionally, and with regards to more contemporary instances, there has been an outburst of interest and demand for accountability by the public in the MPs’ expenses scandal, with the scandal followed by a number of promises from Parliament to make ‘the political elite accountable to citizens’.²⁶ It is interesting, however, to consider Ben Worthy’s comments that such scandals were more of a ‘confirmation’ to the public, rather than a ‘revelation’,²⁷ and as such had little impact on public trust and perhaps, therefore, little impact on the demand for accountability.

Recordkeeping is an integral mechanism that can help to fulfil demands for accountability. FOI, which is one way in which the public can request access to public sector information, can ‘improve accountability’, according to the Lord Chancellor’s Code

²⁴ David Cameron, ‘We Are Creating a New Era of Transparency’, *The Telegraph Online* <<http://www.telegraph.co.uk/news/politics/david-cameron/8621560/David-Cameron-We-are-creating-a-new-era-of-transparency.html>> [accessed 21 June 2015].

²⁵ Bennett, ‘From the Dark to the Light’, p. 191.

²⁶ Andrew Porter, ‘MPs’ Expenses: Gordon Brown Proposes Constitutional Changes in Wake of Scandal’. *The Telegraph Online* <<http://www.telegraph.co.uk/news/newsttopics/mps-expenses/5392110/MPs-expenses-Gordon-Brown-proposes-constitutional-changes-in-wake-of-scandal.html>> [accessed 21 June 2015].

²⁷ Ben Worthy, ‘Evidence to Speaker’s Commission on Digital Democracy’, *Parliament* <<http://www.parliament.uk/documents/speaker/digital-democracy/Digi073BenWorthy.pdf>> [accessed 29 June 2015].

of Practice on the Management of Records, but this is dependent on the records, for, as the code argued, ‘Freedom of information legislation is only as good as the quality of records and other information to which it provides access’.²⁸ Chris Hurley, however, highlights that such a direct link between recordkeeping and accountability is not valid. Though Hurley claims that ‘a connection of some kind exists between recordkeeping and accountability’, he also is aware that ‘[e]ffective recordkeeping cannot *per se* ensure accountability’.²⁹ Furthermore, Hurley claims that ‘effective recordkeeping is a necessary, but not a sufficient, condition for accountability’.³⁰

In this consideration of the term accountability, as part of an introductory conceptual chapter to Open Government Data in the health sector, this report takes account of Hurley’s comments; it is recognised, therefore, that accountability is often seen and even promoted as the basis to a democratic society, following Westernised ideals. Demands for accountability have seemingly increased, although demands are not only contemporary but can also be traced further back, using specific cases as examples. Whilst recordkeeping is a mechanism that can help to improve accountability, including under the *FOIA*, effective recordkeeping cannot ensure accountability, as Hurley has argued. Open Government Data, in the same manner as FOI, can help to answer demands for accountability and, paralleling Hurley’s claims, there is a link between effective recordkeeping and effective Open Government Data, although effective recordkeeping cannot *per se* ensure Open Government Data; as this report will demonstrate, there are a number of other factors involved in Open Government Data, though the integral role of effective recordkeeping should not be dismissed.

²⁸ The National Archives, *Lord Chancellor’s Code on the Management of Records Issued Under Section 46 of the Freedom of Information Act 2002* <<https://www.justice.gov.uk/downloads/information-access-rights/foi/foi-section-46-code-of-practice.pdf>> [accessed 24 June 2015].

²⁹ Chris Hurley, ‘Recordkeeping and Accountability’, in *Archives: Recordkeeping in Society*, ed. by S. McKemmish, M. Piggott, B. Reed and F. Upward (NSW: Charles Stuart University, 2005), pp.223-253 (p. 223).

³⁰ Hurley, ‘Recordkeeping and Accountability’, p. 224.

1.3.3 Governance

The third term that should be considered when defining Open Government Data, for it is often mentioned alongside it, is *governance*. The *OED* defines governance as, ‘controlling, directing, or regulating influence’. Governance, as a term, is often associated with control and to promote the term more positively the adjective *good* is often used as a prefix. For some, such as blog writer Craig Beyerinck, Open Data can ‘reinforce’ good governance, which is ‘used to denote instances where public institutions are completing their tasks in ethical and accountable ways’; for Beyerinck, both Open Data and good governance are terms that ‘are popular buzz words of the modern day’.³¹ In the health sector, governance is often discussed under the label *Information Governance*.

Information Governance, the HSCIC explains, ‘is about setting a high standard for the handling of information and giving organisations the tools to achieve that standard’.³² The HSCIC, ‘the national provider of information, data and IT systems for health and social care’,³³ provides guidance, standards and tools on Information Governance to the health sector, including the self-assessment Information Governance Toolkit. Additionally, the HSCIC regulates a process known as the Information Governance Statement of Compliance (IG SoC), which, they explain, ‘set[s] out a range of security related requirements which must be satisfied’ to allow access to the NHS National Network, N3, an NHS-specific intranet. Chapter Three further analyses both the IG Toolkit and the IG SoC, drawing on evidence provided in the interviews. More recently, an Information Governance Alliance has been established, after recommendations by Dame Fiona Caldicott. Established in 2014, the alliance ‘has been established to bring together resources from member organisations to consolidate specialist knowledge, provide a single

³¹ Craig Beyerinck, ‘Open Data Reinforcing Good Governance’, *Local Interventions Group* <<http://www.localinterventions.org.uk/blog/archives/89>> [accessed 27 June 2015].

³² HSCIC, *Information Governance: Frequently Asked Questions* <<http://systems.hscic.gov.uk/infogov/igfaqs>> [accessed 27 June 2015].

³³ HSCIC, *Home* <<http://www.hscic.gov.uk/>> [accessed 27 June 2015].

source of authoritative and credible guidance and to establish a national information governance network'.³⁴

The report argues that the four terms, Open Government Data, transparency, accountability, and governance, interrelate in a complex manner. Though it has been necessary to discuss these terms in turn, it is clear that, both in theory and practice, it is impossible to isolate the terms and create conceptual boundaries; all four terms inevitably overlap. All of the terms are often promoted in Western cultures as ethically superior, though this causes issues by oversimplifying the concepts as “good”. Open Government Data is a working method that can help to support the principles of accountability, transparency, and information governance in today’s health sector, and effective recordkeeping implicitly underpins the success of Open Government Data. The value of Open Government Data is in its use, not in its publication; for effective re-use, however, the data must possess integrity and be trustworthy, both of which are issues that sit at the heart of Records Management. The link between Open Government Data and Records Management is further analysed in Chapter Three, drawing on evidence from interviews with working professionals at TNA, NHS England, and HSCIC.

Today’s health sector is dominated by these concepts, and current developments are based on promises to increase accountability and transparency. The HSCIC plays a fundamental part in providing guidance, standards and tools on Information Governance in health and social care, especially with the recent establishment of the IGA. Chapter One serves to set out these principles in the context of the health sector in England, not only defining the issues for clarity and a much-needed consensus of understanding, but also drawing on other scholarship to analyse current discussions in Open Government Data

³⁴ HSCIC, *Information Governance Alliance* <<http://systems.hscic.gov.uk/infogov/iga/aboutus>> [accessed 27 June 2015].

discourse which, like the practice itself, is not yet mature and is still very much developing and seeking answers.

1.4 NHS England

The focus of this report is NHS England, with justifications given at the beginning of Chapter Two. A brief contextual introduction to the NHS is needed. The NHS was established in 1948, with the aim of freely ‘bringing good healthcare to all’.³⁵ Affected by pivotal scientific and medical discoveries, such as the discovery of DNA by James D. Watson and Francis Crick, and the invention in vitro fertilisation (IVF), and also affected by major legislative changes, such as the *1967 Abortion Act*, the NHS has changed considerably since its birth.³⁶ No longer ‘one umbrella organisation’ as it was in 1948,³⁷ today’s NHS is sub-divided into NHS England, NHS Scotland, NHS Wales, and NHS Northern Ireland. The use of the determinate article “the”, when referring to “the NHS”, contributes to the false assumption that there is one single NHS, rather than a number of separate organisations, further sub-divided into autonomous Foundation Trusts and also Government-regulated Trusts. Throughout this report, any references to “the NHS” are only ever specifically referring to NHS England, the focus of this report, unless otherwise stated.

More recently, a number of reports have categorically shaped and changed NHS England, most noticeably, perhaps, the Mid Staffordshire NHS Foundation Trust Public Inquiry, chaired by Robert Francis, which scrutinised standards of care at the Foundation Trust and presented some harrowing first-person accounts from victims, and victims’ families, who had failed to receive proper care. A Government response wrote that the

³⁵ NHS, *The History of the NHS in England* <<http://www.nhs.uk/NHSEngland/thenhs/nhshistory/Pages/NHShistory1948.aspx>> [accessed 27 June 2015].

³⁶ Ibid.

³⁷ Ibid.

report ‘made horrifying reading. [...] A toxic culture was allowed to develop unchecked which fostered the normalisation of cruelty and victimisation of those brave enough to speak up’.³⁸ *The Guardian* labelled the scandal as ‘the worst hospital scandal of recent times’, which was not just a typical hyperbolic statement from the media; the article also considered how the report would affect the NHS by prompting ‘much soul-searching’.³⁹ Francis’s report is extensive, comprising of 290 recommendations. Amongst other themes, poor and inadequate recordkeeping was identified as contributing to the system failure, including, as just one example, a lack of consistency in recordkeeping that resulted in families unable to know the time of death of their relative, ‘causing them great distress’.⁴⁰ Overall, the report pushed forward a major change in the NHS, to a ‘more patient centred approach’,⁴¹ of which Open Government Data can be seen as one sub-initiative.

There is a dominant focus on medical records in Francis’s report, a focus that also dominates the NHS too, and rightly so, for people’s lives are dependent on the quality, maintenance, and accessibility, of medical records. Records in the NHS can be divided into medical records and administrative records. Medical records are also the main focus of attention in the *NHS Records Management Code*, and a further analysis of records and recordkeeping is incorporated into Chapter Three of this report.

³⁸ HM Government, Department of Health, *Patients First and Foremost: The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (London: Crown, 2013), p. 5.

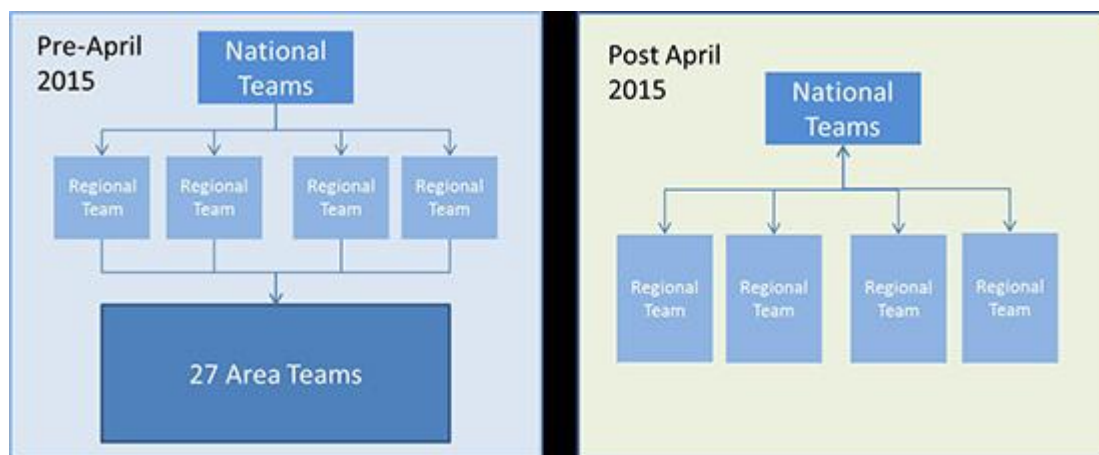
³⁹ Denis Campbell, ‘Mid Staffs Hospital Scandal: The Essential Guide’, *The Guardian Online* <<http://www.theguardian.com/society/2013/feb/06/mid-staffs-hospital-scandal-guide#109>> [accessed 27 June 2015].

⁴⁰ Robert Francis, *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005-March 2009: Volume 1* <http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113447.pdf> [last accessed 30 April 2015].

⁴¹ NHS, *The History of the NHS in England* <<http://www.nhs.uk/NHSEngland/thenhs/nhshistory/Pages/NHShistory1948.aspx>> [accessed 27 June 2015].

The structure of the NHS is perpetually changing and, at the time of writing, NHS England had recently undergone substantial changes, taking effect from April 2015.⁴² Demonstrating that NHS England is not a single entity, but rather a joining together of a number of different pieces to create the jigsaw that is NHS England, the recent structural changes in 2015 subsumed the 27 different area teams into four already-existing regional teams: London, Midlands and East, North, and South (Figure 3). The NHS England website describes this change as promoting operational efficiency, by streamlining the structure through the reduction of one tier.⁴³

Figure 3⁴⁴
Structural Representation of the Regional Teams in NHS England pre- and post-April 2015



This contextual overview of NHS England has indicated the considerable changes experienced by the organisation since its birth in 1948, linking into relevant recordkeeping

⁴² At the point of writing, up-to-date organisational structures were unavailable, although a FOI request was submitted to NHS England well within the legal response time, NHS England failed to provide a response to the request.

⁴³ NHS, *NHS England Regional Teams* <<http://www.england.nhs.uk/about/regional-area-teams/>> [accessed 27 June 2015].

⁴⁴ Ibid.

issues. Complicating this overview of the NHS is the impenetrable language that is sector-specific, as explained in Hayden Thomas's 2013 report:

If the ubiquitous use of acronyms is any indication, on top of the very precise and complex language of medicine, the culture within Health is to create and perpetuate a separate culture of language and concepts from broader government. Most industries now have a jargon that is particular to them but the dialect of health and its liberal peppering of acronyms evolves at a great pace.⁴⁵

Giving only a brief overview, it is hard to capture all the complexities and nuances that combine to create NHS England, a publicly-funded and free-to-all organisation that will forever be a slave to governmental, political, and social pressures.

1.5 Relevant Legislation

NHS England operates within a complex regulatory framework and the final part of this introductory chapter sets out the legislation that is most relevant to this discussion of Open Government Data within NHS England, focussing on DP, FOI, and finally health sector-specific legislation that is the *Health and Social Care Act*.

1.5.1 Data Protection and Freedom of Information

The *DPA* was passed in 1998 and is relevant to information held by both the public and the private sector. At its core, the *DPA* is about protecting the individual and comprises of eight fundamental principles. DP sits at the heart of NHS England Records Management, especially with the recent patient-centred focus. Confidentiality and privacy are ingrained across the whole NHS England spectrum, dictating practice in all areas, and due to the dominating focus on medical records, there is perhaps a tendency for DP issues to demand both time and resources away from other legislation, such as the *FOIA*. Open

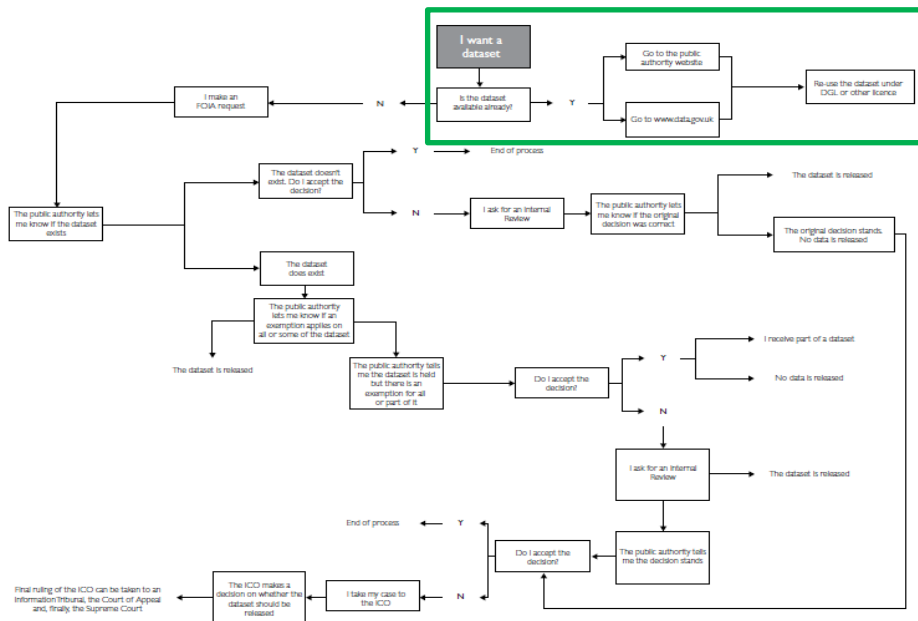
⁴⁵ Hayden Thomas, *What Challenges does the Current Legislative, Regulatory and Organisational Context within the NHS Pose for Records Management?* (London: University College London, 2013).

Government Data does not, and never will, concern private or confidential information. Though there is perhaps a fear that a culture of openness may threaten privacy, thereby threatening the fundamental principles of the *DPA*, it must be stressed that this is an unfounded and entirely unnecessary fear.

There is, however, a more direct link between FOI and Open Government Data in NHS England. FOI, unlike DP, is relevant only to public-sector information, and is fundamentally about access, rather than privacy. Passed in 2000, Patrick Birkinshaw comments that the UK ‘came late to the Freedom of Information Act’.⁴⁶ FOI, like Open Government Data, is centred on an ethos of openness, which is often presented as morally superior, and the two initiatives have developed with a number of, sometimes rather different, benefits in mind, including the benefits of increasing transparency and accountability. However, though FOI and Open Government Data are similar in some sense, there are significant differences, thus a distinction must be drawn. FOI is a reactive process, excluding the proactive release of publication schemes, whereas Open Government Data is only ever a proactive process. Furthermore, FOI is fundamentally about access, whereas Open Government Data is fundamentally about re-use. The close relationship between FOI and Open Government Data is demonstrated in a flowchart from the Government’s *Open Data White Paper* (Figure 4). Though FOI and Open Government Data spring from the same starting point of ‘I want a dataset’, the two initiatives depart in very different directions; the addition of the green rectangle highlights this author’s understanding of the proactive process that is Open Government Data, whereas the rest of the flowchart specifically, and only, depicts FOI.

⁴⁶ Patrick Birkinshaw, ‘Freedom of Information and its Impact in the United Kingdom’. *Government Information Quarterly*, 27 (2010), 312-321 (p. 312).

Figure 4⁴⁷
Flowchart of FOI and Open Government Data



The *Open Government Guide* also highlights the proactive nature of Open Government Data: ‘a government fully engaged in open data is choosing to *proactively* disclose information’.⁴⁸ Robertson considers the difference between FOI and Open Government Data, claiming that issues arise ‘when this modest but worthwhile reform [Freedom of Information] is confused with Open Government’.⁴⁹ Drawing on U.S. President Woodrow Wilson’s quotation that Open Government means ‘open policies, openly arrived at’, for Robertson, Open Government Data is about participation: ‘Such a change [from FOI to Open Government Data] would involve participatory, rather than consultative, democracy, in which the influence of the people could be brought to bear at all stages of the decision

⁴⁷ *HM Government Open Data White Paper: Unleashing the Potential* <http://data.gov.uk/sites/default/files/Open_data_White_Paper.pdf> [accessed 9 June 2015].

⁴⁸ *Open Government Guide, Open Government Data* <<http://www.opengovguide.com/topics/open-government-data/>> [accessed 24 June 2015].

⁴⁹ Robertson, *Secrecy and Open Government*, p. 157.

making'.⁵⁰ As a result, though a link is acknowledged between FOI and Open Government Data, the two are dealt with rather separately in this report. Further analytical discussions of this relationship, drawing on evidence obtained in interviews, comprises part of Chapter Three.

1.5.2 Health Sector-Specific Legislation

DP and FOI affect a wide range of sectors; legislation exists, however, that is specific only to the health sector in England, including the *Health and Social Care Act 2012*. Thomas, writing in his MA thesis, commented that this act caused 'fundamental change' to the NHS.⁵¹ The reforms presented in this act have been described as 'the most significant and far-reaching in the history of the NHS', carried out 'against the backdrop of the biggest financial challenge in its history'.⁵²

A central facet to the act is the management of data in the NHS, including the introduction of pseudonymous data through the use of an NHS unique identifier code attached to all medical records. The act also provided the impetus for a number of record-centred targets, including the ambitious target of a paperless NHS, with all medical records in electronic format, by 2018, a target optimistically set in 2013.⁵³ One aim of this target is to allow online access for all to their individual medical records. Though this promotes access to individual information, it problematically presumes that all have the capability and means for online access.

⁵⁰ Robertson, *Secrecy and Open Government*, p. 21.

⁵¹ Thomas, *What Challenges Does the Current Legislative, Regulatory and Organisational Context within the NHS Pose for Records Management?*, p. 3.

⁵² 'Health and Social Care Act', *The King's Fund* <<http://www.kingsfund.org.uk/blog/2013/04/politics-and-satisfaction-nhs>> [accessed 27 June 2015].

⁵³ TechUK, *Digitising the NHS* <jac.co.uk/wp-content/.../03/Digitising_the_NHS_-_One_Year_On.pdf> [accessed 27 June 2015].

An article in *The Guardian*, written by GP Youssef El-Gingihy, offered a rather pessimistic view of the *Health and Social Act*, drawing mainly on the competitive tendering aspect of the act, which was an attempt to make the NHS more financially viable:

The Health and Social Care Act effectively legislates against free, universal, comprehensive healthcare. Yet this legislation is just one of many planks in the dismantling of the NHS. [...] Once you combine the consequences of the Health and Social Care Act with PFI debts [Private Finance Initiatives], NHS trusts going bust, efficiency savings and cherry-picking, the NHS withers away. Rationing of care will become more widespread until we have a two-tier system in which the haves will take out private insurance and the have-nots will be looked after by a third-class health service.⁵⁴

Any legislation that encompasses pivotal reforms will always have to withstand criticism.

The *Health and Social Care Act*, alongside the *FOIA* and the *DPA*, comprises part of a complex regulatory framework, within which NHS England must operate on a daily basis. The legislation outlined here is felt to be the most relevant to this discussion of Open Government Data in the health sector, but there is a network of other legislation in which the NHS must operate. This discussion of the relevant legislation has argued that Open Government Data explicitly only publishes non-private information for re-use, and this must be clearly highlighted in response to the fears that a move to a culture of openness in the health sector will threaten patient confidentiality and privacy, thus threatening the *DPA* which sits at the heart of NHS England. A move to a culture of openness will not, and never will, threaten these principles. Furthermore, FOI, though in some senses similar to Open Government, is nevertheless distinctly different, with Open Government Data dependent on the mostly voluntary proactive disclosure of information for re-use. As relatively recent legislative developments, FOI and DP have categorically changed the structure and functions on the NHS, as has the *Health and Social Care Act*, which has not been without criticism.

⁵⁴ Youssef El-Gingihy, 'Health Act Means the Death of the NHS as we Know it', *The Guardian Online* <<http://www.theguardian.com/commentisfree/2013/mar/30/health-act-means-death-of-nhs>> [accessed 27 June 2015].

The consideration of relevant legislation concludes this introductory chapter, which has also provided a conceptual discussion of the relevant terms in Open Government Data discourse, as well as a contextual introduction to the NHS itself. The aim of Chapter One has been to establish a foundation of understanding that will underpin the analysis of evidence presented in Chapter Three.

Chapter Two

Methodology

2.1 Reasons to Focus on the NHS

In recent years, the national media have repeatedly criticised practices within the NHS, including criticisms of recordkeeping practices, placing the NHS under ever-increasing levels of scrutiny. As recently as June 2015, Peter Dominiczak, reporting for *The Telegraph*, harshly criticised the sharing of data by the NHS, stating, ‘Hundreds of thousands of people are having their confidential medical data shared against their wishes’; Dominiczak also quoted the Liberal Democrat peer, Baroness Ludford, who asked a question in the House of Lords, amid concerns that data from those who had actively ‘opted-out of having their GP data shared with third parties’ had actually been sold on by HSCIC: ‘Will [the Government] invite the Information Commissioner to investigate this worrying situation, which is undermining patient trust in NHS data sharing, to the detriment of legitimate uses for such data sharing?’.⁵⁵ Exposures of scandals and the subsequent reports have also drawn attention to recordkeeping practices within the NHS, alongside other issues; Robert Francis’s independent inquiry into practices at the Mid Staffordshire NHS Foundation Trust identified and criticised recordkeeping, stating that ‘a number of deficiencies in note-keeping practice were observed too frequently to be attributable to isolated poor practice on the part of individuals’.⁵⁶ Following such reports, openness and transparency have often been identified as solutions to drive up both standards of care and, simultaneously, public trust. For example, in 2013 the Chief Nursing Officer is reported to have said that, ‘absolute transparency is the key to driving

⁵⁵ Peter Dominiczak, ‘Scandal of Shared NHS Data’, *The Telegraph* <<http://www.telegraph.co.uk/news/health/news/11655777/Nearly-1million-patients-could-be-having-confidential-data-shared-against-their-wishes.html>> [accessed 15 June 2015].

⁵⁶ Robert Francis, *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005-March 2009: Volume 1* <http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113447.pdf> [last accessed 30 April 2015].

improvements in standards of care'.⁵⁷ Transparency forms an essential ethos of a number of high-level policies in the NHS, including the *Five Year Forward View*, which is currently a central driver for change in the NHS.⁵⁸

The *NHS* is often seen as a separate entity from government itself,⁵⁹ but openness and transparency are ideals articulated by central government, placing obligations on public sector bodies, such as the NHS. As Ben Worthy rightly argues, '[t]he central "push" or drive for Open Data appears to be Prime Ministerial [...] with the risk that it may dissipate or lose its force when passed through certain instruments in the "sub-policies"'.⁶⁰ Like ripples on the surface of water, the Prime Minister provides the impetus for the Open Government Data agenda, but these ripples inevitably fade the further out they reach. Despite this risk, openness is unequivocally a fundamental part of the 21st-century's political agenda, as illustrated by the statement by David Cameron, then Conservative-Liberal Coalition Prime Minister:

Greater transparency across Government is at the heart of our shared commitment to enable the public to hold politicians and public bodies to account; to reduce the deficit and deliver better value for money in public spending; and to realise significant economic benefits by enabling businesses and non-profit organisations to build innovative applications and websites using public data.⁶¹

Even with the recent change in government, to a Conservative administration, Open Government Data is still firmly rooted in the political agenda; recently, David Cameron

⁵⁷ NHS England, "Absolute Transparency is the Key to Driving Improvements in Standards of Care" says Chief Nursing Officer <<http://www.england.nhs.uk/2013/11/26/transparency/>> [accessed 16 February 2015].

⁵⁸ NHS England *Five Year Forward View* <<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>> [accessed 9 June 2015].

⁵⁹ Hayden Thomas, *What challenges does the current legislative, regulatory and organisational context within the NHS pose for Records Management?* (London: University College London, 2013), p. 13.

⁶⁰ Ben Worthy, *Making Transparency Stick: The Complex Dynamics of Open Data* <<https://opendatastudy.files.wordpress.com/2014/09/ben-worthy-making-transparency-stick-the-complex-dynamics-of-open-data.pdf>> [accessed 11 June 2015].

⁶¹ Simon Rogers, 'Government Data: Full Text of David Cameron's Letter Pledging to Open Up the Datasets', *The Guardian Online* <<http://www.theguardian.com/news/datablog/2010/jun/01/government-data-david-cameron-letter>> [accessed 16 February 2015].

claimed to be driving forward transparency in relation to ‘overseas tax havens’, according to *The Guardian*.⁶²

Open Government Data is not only a current issue in the NHS but also in the wider context of the public sector, though it is the NHS specifically that is the focus of this report. Due to the structure of the NHS, this report focuses on NHS England, and any references made to the NHS are specific to England only, and not Scotland or Wales, unless otherwise stated. Open Government Data environments relating to local authorities have previously been considered in as-of-yet unpublished InterPARES Project research (2014), but there has been little focus on the health sector, adding to the originality and value of this report.

2.2 Literature Review

Open Government, Open Government Data, and Open Data are all subjects that appear extensively in academic discourse, both inside and outside of the Records Management and archival disciplines. This report began with desk-based research in the form of a literature review to develop a detailed understanding of both intellectual heritage and current discussions on Open Government Data, and the overlapping subjects of open government and open data. The literature review underpins this whole report; for example, the literature review underpins the conceptual and contextual introduction in Chapter 1, where the author’s claims are made in comparison to the work of others. Additionally, the literature review influenced the interview schedules, whereby main issues and themes from the relevant literature directly shaped the questions posed to interviewees, discussed further below.

⁶² David Pegg and James Ball, ‘Cameron Crackdown on Tax Havens “Purely Political Gesture”, says Tory Peer’, *The Guardian Online* <<http://www.theguardian.com/politics/2015/apr/15/david-cameron-tax-havens-cayman-islands-david-maclean-lord-blencathra>> [accessed 12 June 2015].

The starting point for the literature review was a previous MA report written by another Archives and Records Management UCL student, Jessica Page, ‘The Role of the Records Manager in an Open Government Environment in the UK’.⁶³ The bibliography from this report served as an initial reading list, directing the author to a range of published sources. From here, the literature review developed by identifying and following seemingly relevant references and footnotes from the literature (chaining), in effect creating a trail, or pathway, of research.

In addition, the literature review was also developed by systemically searching the UCL Library Catalogue, which has access to a wide range of sources and databases, for relevant literature using key terms and phrases, such as the following:

- “Open Government Data”
- “Open government”
- “Open data”
- Open Government Data AND record*
- Record* AND role

The asterisk (*) allowed for a variety of forms of the word *record* to be included in the search, such as *recordkeeper*, *records*, *recordkeeping*, etc. Key websites such as *NHS England* (<http://www.england.nhs.uk/>) were also searched to find relevant policy and guidance documentation, a number of which were also directly referred to in the wider literature. These systematic searches ensured relevant literature was found that had not been found through chaining.

⁶³ Jessica Page, *The Role of the Records Manager in an Open Government Environment in the UK* (London: University College London, 2014).

Finally, the literature review was also shaped by attending a research symposium held at UCL on recordkeeping roles in Open Data and information governance, held on 20 May 2015. Speakers such as Patrick Birkinshaw, Ben Worthy, and James Lowry lectured on a number of current issues, and following this research symposium their work was consulted for the literature review.

From the literature review, a number of writers were identified as influential in the development of this report. For example, James Lowry's chapter, 'Opening Government: Open Data and Access to Information', influenced the interview schedules, specifically his consideration of 'data integrity issues' in Open Government Data⁶⁴. Lowry linked data integrity to traceability, systematic metadata, and data longevity⁶⁵ and the interview schedules, found in Appendix C, drew on these issues in questions 3.1-3.4. The interview schedules were also influenced by another article, Michael Blakemore and Max Craglia's 'Access to Public-Sector Information in Europe: Policy, Rights and Obligations', which argues that access to PSI is posited on the assumption of 'universal access', thus creating a 'digital divide'.⁶⁶ These claims led to questions 3.6-3.8 in the interview schedule, relating to the users of Open Government Data. A number of other useful sources from the literature underpinned Chapter 1; in defining the term Open Government Data, this report was shaped by authors such as Colin Bennett,⁶⁷ Richard A. Chapman and Michael Hunt,⁶⁸ and Harlan Yu and David G. Robinson.⁶⁹ Additionally, the discussion of the necessity of

⁶⁴ James Lowry, 'Opening Government: Open Data and Access to Information', *Integrity in Government through Records Management: Essays in Honour of Anne Thurston*, ed. by James Lowry and Justus Wamukoya (Aldershot: Ashgate, 2014), pp. 161-172 (p. 162).

⁶⁵ Lowry, 'Opening Government', pp. 162-164.

⁶⁶ Michael Blakemore and Max Craglia, 'Access to Public-Sector Information in Europe: Policy, Rights and Obligations', *The Information Society*, 22 (2006), 13-24 (pp. 17, 20).

⁶⁷ Colin Bennett, 'From the Dark to the Light: The Open Government Debate in Britain', *Journal of Public Policy*, 5:2 (1985), 187-213.

⁶⁸ Richard A. Chapman and Michael Hunt, *Open Government in a Theoretical and Practical Context* (Aldershot: Ashgate, 2006).

⁶⁹ Harlan Yu and David G. Robinson, 'The New Ambiguity of "Open Government"', *UCLA Law Review Discourse*, 178 (2012), 180-208.

distinguishing FOI from Open Government Data was influenced by K. G. Robertson,⁷⁰ and Ben Worthy.⁷¹

Though a number of influential writers and sources were identified from the literature review, a number of gaps in the literature were also identified. There was little literature that focused on recordkeeping issues in the NHS, thus an MA report by UCL student Hayden Thomas, ‘What Challenges does the Current Legislative, Regulatory and Organisational Context within the NHS Pose for Records Management’, became a valuable research tool.⁷² Additionally, there seemed to be little literature considering the users and the use of Open Government Data, especially from a UK perspective or a health sector perspective. However, Worthy’s work, including both articles and blog posts, considered similar issues as these and subsequently become a valuable research tool; whilst his research into users of open data tended to concentrate on local government, or drew on empirical evidence from outside of the UK, his work helped to give an indication of users and use of open data, and of attitudes to open data, when there was little other literature to which one could refer. Additionally, Worthy’s articles and blog posts act as a gateway to a wide range of other useful research.

2.3 Qualitative Interviews

Data collection took the form of four qualitative semi-structured interviews which, as Alison Pickard states, are used to seek ‘descriptive, in-depth data that is specific to the individual’, allowing interviewees to ‘respond on their own terms and within their own

⁷⁰ K. G. Robertson, *Secrecy and Open Government: Why Governments Want You to Know* (Basingstoke: Macmillan, 1999).

⁷¹ Ben Worthy, *Open Data Study: Research on Open Data and Transparency* <<https://opendatastudy.wordpress.com/>> [accessed 09 June 2015].

⁷² Thomas, *What Challenges does the Current Legislative, Regulatory and Organisational Context within the NHS Pose for Records Management?*.

linguistic parameters'.⁷³ Open Government Data is a complex subject and qualitative interviews served to break down the complexity of the subject into relevant themes: role and responsibilities of the interviewee, policies and guidance, practice, definitions, and the future. Three of the interviews were conducted face-to-face, and one interview was conducted via e-mail. As Lokman I. Meho has explained, e-mail interviews prevent the interviewer from being able to 'read facial expression and body language', thus perhaps missing some important 'visual or nonverbal cues'.⁷⁴ E-mail interviews, however, 'may safeguard against possible loss of face', and are more cost- and time-efficient, especially with regards to the transcribing stage.⁷⁵ For this report, an e-mail interview opened up the opportunity of collecting data from an individual at HSCIC that, due to time and geographical limitations, would not have been possible otherwise.

Limitations of this report include the small number of interviews conducted, making it difficult, if not impossible, to generalise the findings; during the data analysis and discussion, however, comparisons to wider literature are made to begin to explore any discrepancies and more general similarities.

All four interviewees work in senior positions, either at TNA, NHS England, or HSCIC, and their professional remit and responsibilities are all directly related to the management of records and Open Government Data in the NHS, although the extent of this remit and these responsibilities varies considerably. A number of questions, for example, were beyond the remit of the Senior Advisor for the 20 Years Programme at TNA, specifically questions relating to policy development and implementation of Open Government Data. Consulting those in senior positions at central organisations allowed for a drawing out of expert knowledge, with a specific focus on the development and

⁷³ Alison Jane Pickard, *Research Methods in Information* (London: Facet, 2013), pp. 195-206 (p. 196).

⁷⁴ Lokman I. Meho, 'E-Mail Interviewing in Qualitative Research: A Methodological Discussion', *Journal of the American Society for Information Science and Technology*, 57:10 (2006), 1284-1295 (p. 1289).

⁷⁵ Meho, 'E-Mail Interviewing in Qualitative Research: A Methodological Discussion', p. 1285.

implementation of high-level policies and strategies relating to Open Government Data in the NHS, and a subsequent consideration of the implications for NHS Records Managers.

The methodological approach for the interview process replicates the seven stage approach from Pickard, replicated in Appendix A. Semi-structured interviews were conducted to allow for a comparison of the different responses to the same questions, whilst also providing open-ended questions to which interviewees could respond freely and drive the question in a direction that they felt was most relevant, sometimes unravelling new areas of discussion. Semi-structured interviews also allowed for clarification where necessary and an important part of the interview process was learning from the previous interviews, taking account of Pickard's claim that '[e]ach interview can inform the next'.⁷⁶ Reviewing the previous interviews included amending, re-ordering and re-wording questions where necessary. See Appendix C for the interview schedules.

All three face-to-face interviews were recorded using two pieces of recording equipment, mitigating the risk of technical failures, but due to a failure of battery power, Interview three is divided into two separate recording tracks and the response to question 1.2 has been summarised from the original interview notes. Otherwise, the recordings were the basis for the detailed summary transcriptions (Appendix D). Detailed summary transcriptions are both time-efficient and also simpler to use as only the relevant parts of the lengthy interviews, most of which were approximately one hour, are transcribed. A table structure, rather than prose, was used to further add to the ease of reading and digesting the information.

⁷⁶ Pickard, *Research Methods in Information*, p. 202.

2.4 Research Ethics

The contacts for the interviews were established by NHS England's Senior Data Sharing and Privacy Specialist (Interviewee 3). Following Pickard, 'the purpose of the research and the intended use of the data' was made transparent from the start, using a prepared informed consent form.⁷⁷ See Appendix B for a copy of the informed consent form. The consent form was e-mailed to each participant prior to the interview, alongside a breakdown of the themes that would be discussed in the interview. This ensured that each participant obtained their own copy of the form, which they could read prior to the interview, or to which they could refer later if necessary.⁷⁸ The consent form was read, signed and dated at the beginning of each interview by the participants, and it gave all face-to-face interviewees the option of receiving the detailed summary transcriptions of the interview for verification. Each face-to-face participant consented to the use of their job title and organisation. Each participant asked for the summary transcriptions to be sent to them via email for verification, although not all participants replied. Interviewee one verified the transcription and any subsequent changes are noted in the summary transcriptions.

⁷⁷ Pickard, *Research Methods in Information*, p. 90.

⁷⁸ Ibid.

Chapter Three

Data Analysis and Discussion

3.1 Data Analysis and Discussion

This following chapter discusses the data collected, and is discussed by theme, in the interview schedule order: role and responsibilities; policies; practice. The future of Open Government Data is considered as part of Chapter Four's conclusion. The data is compared across all interviews, to highlight similarities and discrepancies, and is also compared to wider literature, to begin thinking about wider contexts. If it is not otherwise clear, interview numbers (one-four) are used to reference quotations, and the detailed summary transcriptions of the corresponding interviews are given in Appendix D.

3.2 Role and Responsibilities

The role and responsibilities of the four interviewees varied greatly, although all interviewees' remits included practice relating to Open Government Data. Professional remits were explicitly addressed, as were individual backgrounds and qualifications, to understand the interviewees' perspectives. To protect confidentiality, the interviewees are referred to by their job title and organisation.

Interviewee one is a Senior Advisor for the 20 Years Programme at TNA,⁷⁹ a 'quite narrow' role that focuses on the transition to the 20-year closure period of public records to TNA as a place of deposit. The Senior Advisor works specifically with NHS England, and DEFRA.⁸⁰ Due to the narrow focus of the role, a number of the interview schedule questions were not felt to be relevant. For example, questions on metadata and the visualisation of Open Government Data were not felt to be within the interviewee's remit.

⁷⁹ Hereafter, the job title is shortened to TNA Senior Advisor (or Senior Advisor).

⁸⁰ Department for Environmental Food & Rural Affairs (DEFRA).

The Senior Advisor repeatedly pointed to the work of the Information Policy Unit at TNA as more relevant.⁸¹

TNA's Senior Advisor completed a History Degree and a postgraduate archive qualification. The responses of an interviewee trained in archival theory will unavoidably reflect an in-depth understating of very specific archival concepts. With reference to postmodernist theory, any data discussion in this report must acknowledge the "situatedness" of those trained as Archivists, or Records Managers, acknowledging that 'no one can claim objectivity'.⁸² Inevitably, responses will reflect a very particular worldview.

Interviewee two is the Head of Data Policy at NHS England.⁸³ The Data Policy Unit at NHS England covers three main areas of work, according to the NHS England website: information standards, Open Data, and care data.⁸⁴ The HDP commented, however, that information standards were not within the unit's remit, displaying a lack of consistency in information. Due to a recent structural change at NHS England,⁸⁵ the interviewee's job role had changed from the Head of Open Data and Transparency to the HDP; the latter role, the HDP commented, is much 'wider' but still contains a 'very strong focus on Open Data and transparency'. Once settled into the new structure, there is the aim for the unit to 'eventually become almost an internal consultancy or think-tank for NHS England', actively learning 'from the best across the UK and internationally'. The unit's active recognition of international practice was also commented on by others (Interview two), and is also acknowledged on NHS England's website.⁸⁶ The HDP was unaware of parallel units existing in Scotland or Wales; though the unit is explicitly concerned with

⁸¹ Future research would ideally consider the role of this unit in regards to Open Government Data.

⁸² 'Postmodern Worldview', *All About* <<http://www.allaboutworldview.org/postmodern-worldview.htm>> [accessed 4 July 2015].

⁸³ Hereafter, referred to as HDP.

⁸⁴ NHS England, *Data Policy Unit* <<http://www.england.nhs.uk/ourwork/tsd/data-info/data-policy-unit/>> [accessed 9 June 2015].

⁸⁵ Issues relating to the perpetual changing nature of NHS England are discussed in Chapter One. See Appendix E for the organisational chart for the Data Policy Unit.

⁸⁶ NHS England, *Data Policy Unit* <<http://www.england.nhs.uk/ourwork/tsd/data-info/data-policy-unit/>> [accessed 9 June 2015].

learning from others, there seem to be discrepancies in practice, with possible UK-based partnerships being ignored, potentially creating isolated organisational entities across the UK health sector. The HDP's qualifications include two Law degrees. The HDP is a central figure, if not the central figure, with regards to the implementation of Open Government Data in NHS England and, as such, adds value to this report with a rare and detailed insight into organisational policies and practice.

Interviewee three is a Senior Data Sharing and Privacy Specialist⁸⁷ at NHS England, working within the Patients and Information Directorate. The SDSPS's role is wide, covering a number of different responsibilities. When discussing the SDSPS's role, particular attention was paid to the structure of NHS England, as this author had failed to find organisational hierarchies that reflect the recent structural changes at NHS England. The SDSPS commented that, whilst these structural hierarchies 'should be available', any difficulties in finding the hierarchies were merely a reflection of the quick pace of change at NHS England, and submission of a FOI request was recommended.⁸⁸ The SDSPS's qualifications comprised a History degree and an archival qualification; the particular worldview of an individual trained in archival theory must again be acknowledged.

Interviewee four is a Senior Information Governance Advisor at HSCIC,⁸⁹ a role which supports the 'HSCIC's Head of IG' by providing 'internal IG advice about the HSCIC's collection and dissemination of patient identifiable data'. The HSCIC, the Senior IG Advisor explains, 'was established under the *Health and Social Care Act 2013*, and is 'a body which is a legal entity in its own right', which the HSCIC website explains as 'an

⁸⁷ Hereafter, referred to as SDSPS.

⁸⁸ A request was submitted on the 15th June 2015. NHS England failed to provide a response to the request within 20 working days. A response was received after 41 working days. The request, response, and the most recent organisational structures can be found in Appendix E.

⁸⁹ Hereafter, referred to as HSCIC's Senior IG Advisor (or Senior IG Advisor)

executive non-departmental public body'.⁹⁰ HSCIC is subordinate to the NHS in that the NHS can 'issue formal legal "Directions" instructing what data the HSCIC must collect' (Interview four).

HSCIC's Senior IG Advisor possesses a BA degree in History and worked across a range of sectors before joining the Information Commissioner's Office in 2001. The HSCIC is a core organisation in the development of Open Government Data in the health sector, thus adding original value to this report.

3.3 Policies

Questions relating to policies on Open Government Data in NHS England started by initially considering publically-available policies. The questions on policies were not only relevant to those documents explicitly titled "policy", but also to other types of documentation, including guidance and toolkits, thereby acknowledging the more general sense of the word policy as meaning 'a principle or course of action adopted or proposed as desirable' (*OED*).

All the interviews began by considering the link between Open Government Data and Records Management in the health sector, specifically referencing the *NHS Records Management Code (RM Code)*, which was undergoing a review at the point of data collection. The *RM Code* stipulates that it is 'a guide to the required standards of practice in the management of records for those who work within or under contract to the NHS'.⁹¹ The code can apply to both the public and private sectors, and covers both medical and administrative records, 'regardless of the media on which they are held.'⁹²

⁹⁰ HSCIC, *What We Do* <<https://www.gov.uk/government/organisations/health-and-social-care-information-centre>> [accessed 6 June 2015].

⁹¹ *NHS Records Management Code* <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200138/Records_Management_-_NHS_Code_of_Practice_Part_1.pdf> [accessed 4 July 2015].

⁹² *Ibid.*

Records Management, this author argues, should underpin Open Government Data, for the success of openness relies on the quality of the data in the first place. Fundamental principles that sit at the heart of Records Management, such as data integrity and data longevity, are just as relevant to Open Government Data. If Records Management and Open Government Data are viewed as pathways, then they should be entwined pathways, mutually dependent and supportive. As Julie McLeod has argued, ‘we can work with systems designers and creators so that data that is created or collected is captured in ways that make it accessible and useable in legitimate and appropriate ways, through the use of good metadata and interoperable systems’.⁹³ Similar arguments have been voiced elsewhere, including by James Lowry when considering the work of Anne Thurston, who ‘identified the emerging open government movement as a vehicle for bringing wider attention to the value of records management, and saw the contribution that records management could make to the openness agenda’.⁹⁴

The *RM Code* was consistently viewed as separate from Open Government Data in NHS England, viewed as ‘unfortunately different concepts’ (Interview three), in ‘probably slightly different areas’ and ‘not hugely linked’ (Interview one). This separation of what should be mutually supportive agendas is demonstrated when the HDP, who spearheads the openness agenda in NHS England, commented that the Data Policy Unit was ‘not particularly close to the *RM Code* at all’, though the HDP agreed with the claims made by this author that the *RM Code* should fit in with the Open Government Data agenda in the NHS. Adding further, the HDP commented that such codes were, in general, relevant to only a ‘very small number of people’. Like many professional codes, the *RM Code* is merely advice (Interview one), and as such there is little to force compliance.

⁹³ Julie McLeod, ‘Thoughts on the Opportunities for Records Professionals of the Open Access, Open Data Agenda’, *Records Management Journal*, 22:2 (2012), 92-97 (p. 95).

⁹⁴ James Lowry, ‘Opening Government: Open Data and Access to Information’, *Integrity in Government through Records Management: Essays in Honour of Anne Thurston*, ed. by James Lowry and Justus Wamukoya (Aldershot: Ashgate, 2014), pp. 161-172 (p. 161).

The code currently has little to offer the Open Government Data agenda, and it seems the code also has little to offer Records Management itself. Whilst the code was drafted with advice from the Health Archives Group, amongst others,⁹⁵ it is seen as being devoid of basic Records Management principles; one interviewee remarked that, ‘for an organisation that is perpetually going through change they haven’t grasped the concept that if we did things on a functional basis they would be consistent’ (Interview three). Furthermore, it was stated that the code ‘ignores appraisal’; guidance on minimum retention periods for different types of records can be found in the appendices of the code, though these were perceived as having ‘no logic’ (Interview three). Whilst the code is useful in drawing attention to Records Management, the code is viewed by some as a ‘missed opportunity’ (Interview three). Before the code can be joined to the Open Government Data agenda, with the code promoting the importance of Records Management in releasing trustworthy data, the code first needs to increase its audience appeal.

Increasing the audience appeal for Records Management in the NHS, however, is a difficult challenge, perceived as ‘not an easy sell’ (Interview three). To many, Records Management is viewed as ‘business-as-usual’ in the NHS, an inconvenient and resource-intensive aspect of everyday business that ‘nobody cares [about]’ (Interview three). Such connotations may be the result of the push from the profession itself to see Records Management as an “everyday responsibility” that falls within everyone’s remit; supporting this, the TNA argue that ‘getting everyday information management embedded’ in everyday work is a ‘utopia’ to which they are aiming,⁹⁶ but it seems the anticipated utopia has unforeseen complications. Open Government Data, conversely, is experiencing its,

⁹⁵ *NHS Records Management Code*

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200138/Records_Management_-_NHS_Code_of_Practice_Part_1.pdf> [accessed 4 July 2015].

⁹⁶ Rob Johnson, ‘Managing Information: Are You Game?’, *The National Archives: Blog*

<<http://blog.nationalarchives.gov.uk/blog/information-management-gamification/>> [accessed 4 July 2015].

perhaps transient, moment of popularity, viewed not as everyday business but as ‘innovative’ (Interview three).

Adding further to the negative, and incorrect, perception of Records Management in the NHS, is the visibility of the Records Manager. The Records Managers of the NHS are ‘not visible or vocal enough to be involved in’ Open Government Data’ (Interview three). Records Managers are ‘synonymous with filing’ in the NHS and, as such, a space for Records Management in Open Government Data would need to be ‘actively carved out’, perhaps starting with building partnerships with other departments, such as Informatics (Interview three). McLeod argues that ‘the increasing profile and importance of “open access” and “open data” offer new opportunities for information and records managers’,⁹⁷ but such an argument fails to recognise the complex challenges in place, namely the negative categorisation of Records Management in the NHS. Records Management is simply not relevant to Open Government Data in NHS England: ‘It’s like the guy who makes the coffee suddenly offering you an opinion on Albert Einstein’s theory of relativity’ (Interview three). Those promoting Records Management as relevant to Open Government Data should also be cautious that Records Managers, in the traditional sense, are at risk of extinction in the NHS, with roles ever-evolving into Information Governance⁹⁸ (Interview three).

If Records Management has little to offer the Open Government Data agenda in the NHS, then perhaps IG does, with Records Managers working under this guise. Whilst there was an acknowledgement that IG is ‘quite well developed’ in NHS England, with the establishment of regional groups (Interview one), challenges relating to IG, including the use of the Information Governance Toolkit,⁹⁹ were discussed in the interviews. The IGT,

⁹⁷ McLeod, ‘Thoughts on the Opportunities for Records Professionals of the Open Access, Open Data Agenda’, p. 92.

⁹⁸ Hereafter, referred to as IG.

⁹⁹ Hereafter, referred to as IGT.

HSCIC's Senior IG Advisor explains, can promote consistency with its 'basic approach', whilst simultaneously it can be applied to specific circumstances, 'rather than a one size fits all approach' (Interview four), demonstrating the toolkit's flexibility. As with the *RM Code*, the IGT is 'not directly mandated by legislation but it is [...] done without question' (Interview one). Due to this consistent compliance, TNA are looking to build advice into the toolkit, including guidance relating to the 20-year closure rule (Interview one), thus using the toolkit as a "way in" to the health sector and as leverage for their archival aims. Simultaneously, however, interviewees were aware of the challenges posed by the toolkit, which is limited by the self-assessment aspect. Whilst the toolkit certainly has the potential to be useful, by mapping weaknesses and strengths, and by showing potential risk, the toolkit is really only used to measure compliance to the toolkit itself: 'all they are measuring themselves on is whether they have passed the toolkit' (Interview three). The toolkit is dependent on 'attitude' and, whilst it could be 'an engine for change', it is not currently being used as such (Interview three): 'organisations have found it relatively easy to "game" toolkit completion and thus record high toolkit scores which did not reflect the reality of IG practice within that organisation' (Interview four).

The toolkit is seemingly being adhered to consistently, but not necessarily honestly, creating a tension: Why is the toolkit used so consistently if not for the reason it was created? There was an agreement that N3 connectivity forces compliance to the toolkit. N3, an intranet for the NHS, is a 'necessity' in everyday business, providing, amongst other services, 'secure email' (Interview two). Put simply, 'you cannot do business with or as the NHS if you are not N3 compliant', and the IGT is a prerequisite of N3 connectivity (Interview two). However, HSCIC's Senior IG Advisor considered the reasons for compliance differently: 'the idea of patient confidentiality is one that has been at the heart of doctor patient relationship since time immemorial', with experiences such as the 2008

‘loss of data on over a third of the UK’s population’ forcefully ensuring future compliance (Interview four). Compliance with the toolkit overall, however, seems to have little to do with recordkeeping or IG and, as such, there seems little opportunity to extend the capacity of the toolkit to include Open Government Data within its remit.

The HDP raised a further issue with IG in general: ‘IG has been boiled down to nothing but security and privacy, whereas eight years ago it was much wider than that and it encompassed things like data management as well’, and the toolkit itself ‘has played a part in [that] narrowing’ (Interview two). NHS England’s HDP would like to see IG in the health sector pull ‘back a bit to that wider and broader, more holistic, view’ of previous years, which would take account of not only the ‘technical aspects’ but also ‘the wider ethical implications of IG’. A wider, more holistic, and ethically-sensitive approach to IG in the health sector would certainly help to create a space for Open Government Data.

Though both the *RM Code* and the IGT are not mandated by legislation, the work of HSCIC is, with policies dictated by ‘s260 of the *Health and Social Care Act* to publish all the aggregated and anonymised data it receives under a Direction from the Department of Health or NHS England’ (Interview four). As such, the monitoring and review of HSCIC’s policies do not follow the same processes as “optional” or organisationally-led policies that exist at NHS England. Organisational policies at NHS England relating to Open Government Data are not mandated by legislation, but they may still hold the power to push forward the openness agenda. First and foremost, policies on Open Government Data in the traditional and tangible sense do not exist in NHS England, and the HDP has not written any such policies. The work of the Data Policy Unit is seen as the ‘nearest to an organisational policy [that] you are going to get’ (Interview three). As the HDP explained, ‘policies go into a dusty place. They tend to be too large and utterly impregnable’ (Interview two). Instead of an isolated and underused policy, that would be relevant to only

a minute user group, NHS England is taking a more complex and more challenging approach to policy development; Open Government Data is ‘not something somebody over here does in a little box and it is not something somebody goes and pulls out a “How To” guide on’ (Interview two). Instead, transparency¹⁰⁰ is being achieved in NHS England through the embedding of the openness agenda across all work streams, ‘a case of building in rather than creating something separate and different’ (Interview two). Included in this approach is the embedding of the agenda across a range of different traditional written policies, with examples such as the *Five Year Forward View* document given, ‘which absolutely enshrines transparency’ (Interview two). Though perhaps a more difficult route, this embedding of the agenda across the working spectrum should surely, if successful, be more effective.

This embedding, however, faces a number of complex challenges. Ben Worthy has considered the possibility of Open Data policies ‘sticking’,¹⁰¹ arguing that Open Data is in its infancy and these early years are critical to later success or failure.¹⁰² The interviewees agreed that Open Government Data policy is in its infancy in the UK, ‘not yet [...] very mature’ (Interview two), and still at a ‘best intentions’ stage (Interview three). One comment was that Open Government Data is ‘too new of a concept and is still something that is being chewed over’, with people still trying to answer, ‘what does Open Data mean in health?’ (Interview three). Currently, policy development is severely affected by a widespread existence of nervousness around the concept of Open Government Data, commented on in all interviews, further fuelled by, what has been described by Janssen et

¹⁰⁰ The HDP repeatedly used the phrases Open Government Data and transparency synonymously, seeing Open Government Data as a ‘mechanism’ for achieving transparency (Interview two).

¹⁰¹ Ben Worthy adopts the term “Open Data” in his writing, rather than the term “Open Government Data”, as used by this author.

¹⁰² Ben Worthy, *Making Transparency Stick: The Complex Dynamic of Open Data* <<https://opendatastudy.files.wordpress.com/2014/09/ben-worthy-making-transparency-stick-the-complex-dynamics-of-open-data.pdf>> [accessed 4 July 2015].

al as, ‘a recalcitrance to change’.¹⁰³ The SDSPS commented that ‘the more open you get, the more nervous people get’, and HSCIC’s Senior IG Advisor explained that ‘already there are large numbers of people who do not want their identifiable data used for anything other than their direct care’; such resistance is detrimental, for it impacts the HSCIC’s ‘ability to collect patient information in the first place’ (Interview four). Trust in organisational bodies such as HSCIC is crucial, as commented on by HSCIC’s Chief-Executive: ‘Equally required is public trust in our custodianship of national data and the controls we have put in place’.¹⁰⁴

Nervousness may also exist due to a misunderstanding of the term Open, which some wrongly believe refers to the opening up of personal data. As the HDP explained, ‘it absolutely can’t be’ about personal or identifiable data (Interview two), which should be ‘an obvious caveat’ (Interview one). Though it may seem obvious to those working with Open Government Data, there is a need to make this caveat more explicit. Part of the Data Policy Unit’s remit, therefore, is to educate others to mitigate this lack of knowledge, which Janssen et al have previously identified as one of a number of ‘barriers for not publicizing data’.¹⁰⁵

Also affecting policy development is a misunderstanding of the value of re-use in Open Government Data. There is a tendency to dump large quantities of data without the necessary support or quality, simply believing ‘the rationalistic premise that more information leads to more benefits’, creating what Blakemore and Craglia have coined a ‘[b]uild it and they will come mentality’.¹⁰⁶ Furthermore, Janssen et al have commented that ‘Policy-makers prefer to simply make data available. [...] This myth challenges that

¹⁰³ Marijn Janssen, Yannis Charalabidis, and Anneke Zuiderwijk, ‘Benefits, Adoption Barriers and Myths of Open Data and Open Government’, *Information Systems Management*, 29 (2012), 258-268 (p. 261).

¹⁰⁴ NHS England, *News* <<http://www.england.nhs.uk/2014/11/13/leaders-transform/>> [accessed 9 July 2015].

¹⁰⁵ Janssen et al, ‘Benefits, Adoption Barriers and Myths of Open Data and Open Government’, p. 262.

¹⁰⁶ Michael Blakemore and Max Craglia, ‘Access to Public-Sector Information in Europe: Policy, Rights, and Obligations’, *The Information Society*, 23 (2006), 13-24 (pp. 15, 20).

data can be made available without additional activities'.¹⁰⁷ The HDP is aware that the NHS, alongside other industries, 'is awful for just dumping data and leaving it'. The HDP educates others to better understand that 'the more they put into the publication the better', as well as trying to find those individuals who will 'remain involved' beyond publication. If Open Government Data were a race, then there is a tendency to view it as a short-distance sprint, where speed is key, and the finish line is the release of the data. In reality, however, Open Government Data is a marathon, where endurance is key, and, due to the need for constant and continuous support, the finish line is not even visible.

Perhaps the most significant challenge that the health sector faces when developing Open Government Data policies is the widespread fear of the media, which inhibits any real progress. As Worthy has argued, Open Data policies could fail due to a fear of the data being used negatively by the media, a fear which has carried through from FOI, a claim Worthy substantiates by referencing Tony Blair's comments on FOI:

The truth is that the FOI Act isn't used, for the most part, by "the people". It's used by journalists. For political leaders, it's like saying to someone who is hitting you over the head with a stick, "Hey, try this instead", and handing them a mallet.¹⁰⁸

As Worthy reflected, Blair's comments are 'demonstrably untrue', and have added to a 'distorted view' of FOI.¹⁰⁹ Janssen et al have also commented that 'the government is compared to an oyster that automatically closes up when approached'.¹¹⁰ This distorted view has seemingly bled into Open Government Data, for the data collection demonstrates that a fear of the media still persists. TNA's Senior Advisor explains how TNA are now more conscious of the role of archives in maintaining accountability since scandals, such as the Jimmy Saville scandal and the Hillsborough case, dominated the news. Reports that

¹⁰⁷ Janssen et al, 'Benefits, Adoption Barriers and Myths of Open Data and Open Government', p. 265.

¹⁰⁸ Ben Worthy, *Making Transparency Stick: The Complex Dynamic of Open Data* <<https://opendatastudy.files.wordpress.com/2014/09/ben-worthy-making-transparency-stick-the-complex-dynamics-of-open-data.pdf>> [accessed 4 July 2015].

¹⁰⁹ Ibid.

¹¹⁰ Janssen et al, 'Benefits, Adoption Barriers and Myths of Open Data and Open Government', p. 258.

were constructed during investigations into the Jimmy Saville case, for example, made a link between the care of records and maintaining accountability, as there had been a number of difficulties in trying to access ‘basic information’ during the investigation (Interview one). Comments were also made regarding the changing remit of the HSCIC in light of data sharing scandals (Interview four). The HDP in NHS England works to mitigate the ‘unhelpful behaviour of the press’ who, in looking for the ‘worst’, carry out a ‘witch-hunt first’ when data is released (Interview two). Aware of the tendency for information to be manipulated and misconstrued, there were comments from interviewees reflecting on the need for ‘context, to stave off *Daily Mail* headlines’ (Interview three). For example, the release of mortality rates under individual surgeons may be particularly high for those surgeons who are willing to take on the most complex and life-threatening of surgeries (Interview three). If the media persist in reporting mortality rates with this context missing, then the health sector could suffer with surgeons refusing to continue undertaking complex surgeries. Providing context is essential and it demands the expertise and knowledge of trained Records Managers and Archivists; further discussions can be found below when considering practices of Open Government Data.

Open Government Data policy development in NHS England currently relies on only a few central figures. Tim Kelsey, heading the Patients and Information Directorate, is repeatedly mentioned as a champion (Interview one; Interview two), with the support of a few key practitioners (Interview three).¹¹¹ Whilst any cultural change that is on the same scale as Open Government Data will always need to be spearheaded by individual

¹¹¹ Examples of a champion practitioner includes the successor to the practice previously ran by Dr Harold Shipman, Shipman being the former family doctor who murdered an estimated 250 of his patients over 23 years. There was an awareness from the interviewee that this practitioner was in an exceptional circumstance in taking over what was Dr Harold Shipman’s practice, where there is a need to re-build a large amount of public trust, and openness and transparency are ways in which this public trust can be re-built (Interview three).

David Batty, ‘Q&A: Harold Shipman’, *The Guardian Online*
<<http://www.theguardian.com/society/2005/aug/25/health.shipman>> [accessed 6 July 2015].

champions, especially in a ‘risk-averse culture’,¹¹² this person-dependency is inevitably creating a fragile system that is subject to collapse. As the SDSPS explained, the ‘NHS works on people not systems. You take the people out and it doesn’t work’ (Interview three). Though acknowledging that a person-dependent approach is sometimes ‘necessary’ as a catalyst for change, the current system in NHS England is extremely person-dependent (Interview three), resulting in a worryingly fragile system that teeters and balances on a few central blocks, none more so central than the HDP, who not only champions the importance, usefulness and value of the agenda, but also strives to embed the agenda into working practices that are spread right across NHS England.

3.4 Practice

Having discussed the policies in place for Open Government Data in the health sector, this report will now discuss the practice of Open Government Data, specifically discussing metadata processes, data integrity, electronic records, and users of Open Government Data.

As mentioned, there is a need to provide context to Open Government Data to prevent misrepresentation, especially by the media. Providing context to data is also necessary for a number of other reasons. As Janssen et al have discovered, ‘no explanation of the meaning of the data’ is one of a number of ‘barriers for not publicizing data’.¹¹³ Furthermore, ‘information may appear to be irrelevant or benign when viewed in isolation, but when linked and analysed collectively it can result in new insights’.¹¹⁴

Metadata¹¹⁵ is essential to make the user experience of Open Government Data efficient, clear, and useful. As Lowry has explained, metadata should be captured upon

¹¹² Janssen et al, ‘Benefits, Adoption Barriers and Myths of Open Data and Open Government’, p. 265.

¹¹³ Ibid.

¹¹⁴ Ibid.

¹¹⁵ ‘Metadata is commonly defined as "data about data." Metadata is frequently used to locate or manage information resources by abstracting or classifying those resources or by capturing information not inherent

creation, for ‘retrospective capture [...] is not affordable or feasible’.¹¹⁶ Additionally, a lack of metadata can result in data being ‘unconnected to the context of its creation, left without the essential information needed for its interpretation, and irretrievable’.¹¹⁷ Significantly, however, little was known about the metadata processes in place for the release of data for re-use in the health sector. Both TNA’s Senior Advisor and HSCIC’s Senior IG Advisor felt that the metadata questions were beyond their remit. Worthy’s research into the publication of local authority data has shown that a lack of standardised metadata processes is not specific to the health sector: ‘Most felt that the data needed to be linked, contextualised and localised’.¹¹⁸ The HDP explained, however, that the metadata processes were ‘dependent on the nature of the data’ (Interview two), indicating that there is a spectrum of metadata processes, rather than one “standardised” process. Whilst there are ‘official’ and ‘strict’ processes in place for applying metadata to national and official statistics, there is only guidance and encouragement of good practice in place for other data; such guidance includes ‘formulaic’ checklists encouraging standardisation of, for example, date ranges and data sources (Interview two). This “other data” that is not national statistical data constitutes an unfathomably huge amount of data. Only relying on encouragement and advice will inevitably lead to inconsistent compliance and inconsistent data quality. A variation in both compliance and quality threatens the success of Open Government Data; as explained, the value of Open Government Data is in its re-use, and re-use is only truly possible when the data is combined with context, a claim further supported by Janssen et al’s research.¹¹⁹

in the resource’. *Society of American Archivists* <<http://www2.archivists.org/glossary/>> [accessed 19 August 2015].

¹¹⁶ Lowry, ‘Opening Government: Open Data and Access to Information’, p. 163.

¹¹⁷ Ibid.

¹¹⁸ Ben Worthy, *David Cameron’s Transparency Revolution* <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2361428> [accessed 12 June 2015].

¹¹⁹ Janssen et al, ‘Benefits, Adoption Barriers and Myths of Open Data and Open Government’, p. 265.

The majority of the data published for re-use in NHS England is in a mostly processed form (Interview two), thus the data published is artificially managed and compiled, rather than naturally accrued and released in its raw form. There are, however, specific justifications for the high volume of processed data published by NHS England. As the SDSPS commented, ‘there is always some form of management’ of data, sometimes as a result of data quality issues with the raw data itself (Interview three). If basic Records Management principles were accounted for at the point of data creation then such issues would be less problematic. TNA’s Senior Advisor also commented that raw data is not always ‘particularly easy to get to grips with [but] can be developed into something which is’. The HDP and HSCIC’s Senior IG Advisor also explained, that, of course, data was processed due to the inclusion of personal and identifiable information, thus artificially managing the data was necessary to comply with DP.

Though processed, the data ‘should say what data it was that they used in the production’ (Interview two), allowing users to trace the data back to a raw source. As Lowry has explained when arguing for the importance of traceability, ‘Open data is predicated on citizens trusting the information provided by government. In order for data to be trusted, it must be possible to trace the data back to verifiable sources of evidence’.¹²⁰ Despite the claims from interviewees that traceability should be possible, more detailed research into practice would help to unpick just how robust the traceability processes in the health sector are, prompted by one comment that ‘in a lot of circumstances it will not be possible to go back to individual level data’ (Interview four).

NHS England aims to have all medical records in electronic format by 2018, allowing patients access to their own health records. This paperless healthcare utopia is proposed on an assumption of universal access to digital technology:

¹²⁰ Lowry, ‘Opening Government: Open Data and Access to Information’, p. 162.

In just four years, every citizen will be able to access their health records at the click of a button, detailing every visit to the GP and hospital, every prescription, test results, and adverse reactions and allergies to drugs. Patients will also be able to record their preferences and thoughts alongside official medical notes.¹²¹

In reality, however, a fully-electronic healthcare system will only create a digital divide, forcing a gulf between those who can access their electronic health records, and those who cannot. Blakemore and Craglia have considered the same issue of assumed digital access, with reference to the UK Government.¹²²

The interview schedules considered whether the same attention with regards to format was being applied to administrative records as well as medical records, for this would impact the Open Government Data agenda. The data collection demonstrates that medical records are a ‘priority area’ in NHS England (Interview one), though administrative and medical records cannot always be so neatly divorced (Interview two). A focus on patient information is understandable for, as Luciana Duranti has argued, medical records can literally be a matter of life or death.¹²³ Open Government Data assumes that data can be retrieved and accessed over time, but there seemed little concern in the interviews for digital fragility and the need to actively migrate information before it is lost. TNA’s Senior Advisor commented that debates concerning continued accessibility were ‘in general at an early stage’. A lack of discussion could be because, despite the ‘brave’ 2018 fully-electronic target, the NHS is still very much operating with a paper system, ‘or at best hybrid’ (Interview one). Suggesting that debates regarding the migration of data will occur only in reaction to a ‘critical’ situation, the Senior Advisor at TNA commented that digital preservation has been actively ‘parked’; TNA, however, are adding guidance into the *RM*

¹²¹ NHS England, *News* <<http://www.england.nhs.uk/2014/11/13/leaders-transform/>> [accessed 9 July 2015]. Underlining is this author’s own emphasis.

¹²² Blakemore and Craglia, ‘Access to Public-Sector Information in Europe: Policy, Rights, and Obligations’, p. 20.

¹²³ Luciana Duranti, ‘Shadow of Doubt’, *InterPARES* <http://www.interpares.org/display_file.cfm?doc=ip1-2-3_canada_dissemination_pr_duranti_frontier_5_2008.pdf> [accessed 21 July 2015].

Code relating to migration. Again, there is an obvious opportunity for Records Managers to contribute significantly to the Open Government Data agenda in the health sector, and elsewhere, by offering up their expertise, especially with regards to digital continuity. Whereas the Open Government Data field is only just beginning to think about and question digital continuity, the Records Management field has been discussing digital continuity for a number of years now.

Despite the current popularity of Open Government Data, there has been little focus given to the actual use of Open Government in practice. The data collection suggested that there is currently a low uptake and seemingly little interest in Open Government Data in the health sector. The HDP commented that ‘re-use isn’t as good as we would like to see it’, providing the example that prescription data ‘doesn’t get a huge amount of re-use’, thus Open Government Data is not currently ‘translating into the sort of benefits we would like to see yet’ (Interview two). Worthy has found similar instances in his study of local governments, with 60% of participants describing ‘use of spending data as “low” or “very low”’.¹²⁴ Worthy reflects on the complex reasons as to why use of data may be so low, firstly considering the problematic way in which information is displayed.¹²⁵ Certainly, the HDP also commented that health sector information is often put out in a ‘clunky’ way, which is neither ‘modern’ nor ‘efficient’. Worthy also considers public motivation, which could be a key barrier to Open Government Data, drawing on one of the quotations from a respondent in his research: “I assume that most people are not the slightest bit interested in spending their spare time poring over this type of material”.¹²⁶ For some, Open Government Data is not about monitoring users (Interview two)¹²⁷ but, as with any new

¹²⁴ Ben Worthy, *David Cameron’s Transparency Revolution* <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2361428> [accessed 12 June 2015].

¹²⁵ Ibid.

¹²⁶ Ibid.

¹²⁷ Ben Worthy comments that Tom Steinberg has expressed a similar concern over ‘the focus on use numbers across the Open Data reforms’. Ibid.

initiative, monitoring and evaluation are crucial for effective development. The data collection demonstrates that there is ‘not really’ an average user of Open Government Data in NHS England (Interview two), and neither is there a ‘conscious aim’ at the TNA in targeting information towards an average user (Interview one). Agreeing with Worthy’s claims that ‘there is no sign of an “army” of auditors’, and that auditors are ‘very much atypical’,¹²⁸ the HDP commented that the data released is ‘aimed at a relatively technical audience’, and ‘re-use in earnest’ includes only a ‘few main groups’, including developers, analysts, charity activists, health-watch members, and ‘super-engaged patients’. There seems little uptake from the “general public”, despite the argument that data is released to allow citizens the power of scrutiny. HSCIC’s Senior IG Advisor also commented that there is not an average user in mind when data is published: ‘It could be anyone from large corporate users to small but effective developers such as “Openly local”’. As Worthy has argued, Open Government Data is currently only engaging ‘a small network of engaged people’, who tend to have a ‘very particular’ background, usually with a ‘pre-existing activist base’.¹²⁹ Extensive monitoring would indeed breach the transparency ethos on which many Open Government Data initiatives are built, but basic monitoring of numbers and feedback from users is essential,¹³⁰ especially in providing answers to what should be a very relevant question – why is there so little interest in Open Government Data? This report recommends that further research considers use of Open Government data, across a range of different sectors, to develop a deeper understanding of the agenda’s place within society; a deeper understanding will, in turn, help to advance and develop the agenda in the future.

¹²⁸ Ibid.

¹²⁹ Ibid.

¹³⁰ Worthy argues that ‘One group that can provide feedback is the users themselves’. Ben Worthy, *Making Transparency Stick: The Complex Dynamic of Open Data* <<https://opendatastudy.files.wordpress.com/2014/09/ben-worthy-making-transparency-stick-the-complex-dynamics-of-open-data.pdf>> [accessed 4 July 2015].

Having considered both policies and practice, this report will mirror the structure of the interview schedules by discussing the possible future of Open Government Data, which forms part of Chapter Four's conclusion.

Chapter Four

Conclusion

4.1 The Future?

Acknowledging the current infancy of Open Government Data, it is interesting to consider the potential future of the agenda, though any considerations are purely speculative. Currently, there is little legislation to underpin the Open Government Data agenda in the health sector.¹³¹ Links between FOI and Open Government Data have been made throughout this report and are evident in the data collection, with the TNA Senior Advisor commenting on the ‘grey area’ between the two concepts, and NHS England’s HDP commenting that Open Government Data is essentially the proactive release of any information that is ‘FOI-able’. Unlike FOI, Open Government Data is policy-led and there is little to force compliance. Whilst legislation could help to clarify what exactly is meant by Open Government Data (Interview three), there is little hope in developing concrete legislation until there is an agreed notion of what is meant by Open Government Data. As NHS England’s HDP explained: ‘The different definitions are all part of a continuum and even big organisations fundamentally disagree about definitions’. Interviewees commented that a number of key questions still remain unanswered: ‘What does Open Data mean in health?’, ‘What do we think more data will do?’ (Interview three). ‘What information can most usefully be published? What form is most useful to the people that want to use it?’ (Interview one).

Cabinet Minister Francis Maude has made his intentions clear for FOI to be made ‘redundant’ by Open Government Data in the future: ‘My view is that we should be proactively making public everything that is appropriate. You should make redundant the

¹³¹ Excusing the remit of the HSCIC which is explicitly in reference to specific legislation (Interview four).

need for people to ask for access to information'.¹³² How is it possible to define what is “appropriate”? As Paul Gibbons has argued, ‘How do people challenge that decision? What if people have further questions about the information that has been disclosed?’.¹³³ FOI provides a legislative right of access to public-sector information in a way that Open Government Data does not. Though Blair calls FOI his biggest mistake, it is without doubt an important milestone in the history of British legislation, and one that should never become “redundant”. Without FOI, a government-led, rather than citizen-led, system could be open to abuse, whereby those with power ultimately determine public access to information, thus perpetuating prevailing notions of power.

There were interesting comments in the interviews in response to Maude’s claims. TNA’s Senior Advisor commented that it is ‘too early’ to speculate as to whether FOI will be made redundant by Open Government Data, also commenting that there is a ‘certain degree of consensus’ across the political spectrum with regards to Open Government Data, linking into Worthy’s comments that Open Data is essentially a ‘voteless’ initiative: ‘although it attracts support from all sides of the elite political spectrum, Open Data brings no electoral advantage’.¹³⁴ As such, whilst rhetoric may often quote Open Government Data as a ‘cornerstone of administrative and political reform’,¹³⁵ government backing of an initiative that will not result in electoral votes, and thus will not help to guarantee seats in Parliament and guarantee political power, is bound to be limited.

¹³² Paul Gibbons, ‘FOI v Open Data?’, *FOI Man* <<http://www.foiman.com/archives/1369>> [accessed 20 July 2015].

See also, ‘Francis Maude: “I’d like to make FOI redundant”’, *Information Management* <<http://www.information-age.com/technology/information-management/2111138/francis-maude%3A-%22id-like-to-make-foi-redundant%22>> [accessed 20 July 2015].

¹³³ Paul Gibbons, ‘FOI v Open Data?’, *FOI Man* <<http://www.foiman.com/archives/1369>> [accessed 20 July 2015].

¹³⁴ Ben Worthy, *Making Transparency Stick: The Complex Dynamic of Open Data* <<https://opendatastudy.files.wordpress.com/2014/09/ben-worthy-making-transparency-stick-the-complex-dynamics-of-open-data.pdf>> [accessed 4 July 2015].

¹³⁵ *Ibid.*

Maude's comments may reflect a political fear of FOI; Central Governmental support of Open Government Data could merely be a strategy to push scrutiny outwards to local government (Interview two). In this sense, Open Government Data acts as a blanket by hiding a strongly 'political agenda' (Interview three), a political agenda which is hard to ignore when considering Blair's hostile comments towards FOI, discussed previously. For the SDSPS, Open Government Data 'feels narrowly political' and to make FOI redundant is to deny a 'legal right to request'.

4.2 Conclusion

At this early stage, Open Government Data needs to become an 'accepted concept' (Interview three) before any real progression can take place. An air of fear still exists, possibly as a residue from FOI, acting as an inhibitor. Many do not understand exactly what is meant by the term "Open Government Data", especially in the sensitive area that is the health sector. Even those advocating the open agenda display a lack of intellectual consistency regarding the term, especially with regard to how much emphasis should be placed on the re-use aspect. There may never be an agreed concept, but to embrace what some have perceived as a more ambiguous term, as this report has done, is to embrace a more "fuzzy" approach that reflects reality, a reality where the technology of Open Data and the politics of Open Government cannot be neatly separated. A fuzzy approach also embraces overlapping of sister concepts such as accountability, transparency, and governance.

Whilst there are some central figures pushing forward Open Government Data in NHS England, the existing person-dependent approach is fragile. In promoting a better understanding of Open Government Data, and expelling the myth that it concerns the sharing of personal data, there is an opportunity to include others, thus widening the burden

beyond a few central figures. Though there currently seems little space for Records Management in the Open Government Data agenda in the health sector, the potential for a meaningful conversation with Records Managers is clear. Offering support, however, is complex, and Records Managers would actively need to carve out a space. There are a number of negative connotations attached to Records Management in the NHS and, as such, it is recommended that support is simply offered under another guise, such as Data Manager or Open Government Data Specialist, in effect embarking on the Open Government Data campaign *tabula rasa*, with a blank slate. To remain relevant, it is imperative to adapt, in this instance evolving to think and communicate in terms of a “data paradigm”. As Michael Crichton, author of *Jurassic Park*, wrote so eloquently of the concept of a paradigm,

as scientists used it the term meant something more, a world view. A larger way of seeing the world. Paradigm shifts were said to occur whenever science made a major change in its view of the world. Such changes were relatively rare, occurring about once a century. Darwinian evolution had forced a paradigm shift. Quantum mechanics had forced a smaller shift.¹³⁶

Perhaps Open Government Data will force a paradigm shift in the Records Management world, for there is a very real opportunity for Records Management to make a meaningful contribution to Open Government Data. Whilst Records Management and Open Government Data may have previously been running as separate pathways, similar questions are now being asked by both pathways, especially regarding digital longevity and continued accessibility, data integrity, and metadata.¹³⁷

Shifting to a data-based paradigm would hopefully provide the momentum to steer Open Government Data towards more complex practices, which would include the linking of data rather than just the bulk-publishing of single data sets, as well as carefully

¹³⁶ Michael Crichton, *Jurassic Park* (London: Random House, 2006), p. 384.

¹³⁷ James Lowry, ‘Opening Government: Open Data and Access to Information’, *Integrity in Government through Records Management: Essays in Honour of Anne Thurston*, ed. by James Lowry and Justus Wamukoya (Aldershot: Ashgate, 2014), pp. 161-172.

considering the re-usability of the publication format (Interview two). These developments should be implemented in light of successful international practice, such as the noteworthy examples of Open Government Data in Norway; as Lowry has explained, ‘Norway’s technology framework streamlines access to active records through the OEP [Offentlig Elektronisk Postjournal] and to inactive records through the national archives’.¹³⁸

More mature policies would help to fulfil some of the anticipated benefits of Open Government Data, which during these early stages have not come to fruition (Interview two). These anticipated benefits include the ability to maintain accountability through standardised retention schedules and the permanent preservation of archives in places of deposit such as TNA (Interview one); ‘building public confidence’, ‘reducing corruption’, and ‘creating efficiency’ (Interview two); an ‘informed public’ who can ‘scrutinise bad practice and support good practice’ (Interview three); and improving transparency to result in system improvements with data showing ‘where improvements can be made’ (Interview four). There was little evidence that these benefits had been realised, as of yet: ‘I am aware of stories of some benefits but I have no evidence to hand at this time’ (Interview four). The HDP, however, explained how Open Data can enable people to find solutions, providing the example of the Obesity Data Challenge,¹³⁹ where the data published for re-use ‘does nothing more than say how obese each nation is’, but the aim of the project is for users to correlate the information released with other datasets, essentially linking datasets, to ‘think a bit more creatively about the data they are looking at’ and to ‘think about obesity in new ways’ (Interview two). As the SDSPS explained, the HDP is propelling the Open Government Data agenda forward by tapping into current issues in the health sector: ‘[the HDP] is socialising the organisation to the concept of Open Data and choosing things that ring bells, such as obesity’ (Interview three).

¹³⁸ Lowry, ‘Opening Government: Open Data and Access to Information’, p. 166.

¹³⁹ *Rewired State: Obesity Data Challenge* <<http://www.rewiredstate.org/static/packs/main.pdf>> [accessed 9 June 2015].

At such early an early stage, it is crucial that Open Government Data is continuously monitored and further research undertaken. This report has considered NHS England, but it is recommended that further research considers the other organisational entities that make up the UK's health sector. Furthermore, future research should look at international practice to establish an understanding of Open Government Data on an international stage, and providing examples of best practice from which the UK can learn. The data collection in this report has shown that there is a lack of interest from the general public in Open Government Data; though monitoring is not what Open Government Data is about (Interview two), further research into users would help to push forward an agenda that is more relevant. What data do people wish to view and use? In what format do people wish to view data? In what way do people wish to re-use the data?

In answering these questions, there is a real chance for Open Government Data to make a significant contribution to society. Though further research and feedback from users would help Open Government Data to have a more meaningful space in today's culture of openness, it will never, and should never, replace FOI; though the two are posited on citizen access to information for a greater "democratic good", FOI stands as a basic human right, currently enshrined in EU-led legislation, in a way that Open Government Data does not. Open Government Data is not legislation-driven, but is policy-driven and, as such, is flexible and able to adapt as a result of further research and as deeper understandings develop. The future success of Open Government Data is uncertain, but in its uncertainty there is something exciting – the prospect of a future that will truly be open, where access to information for re-use is a given that drives the economy, innovation, participation, transparency, and accountability.

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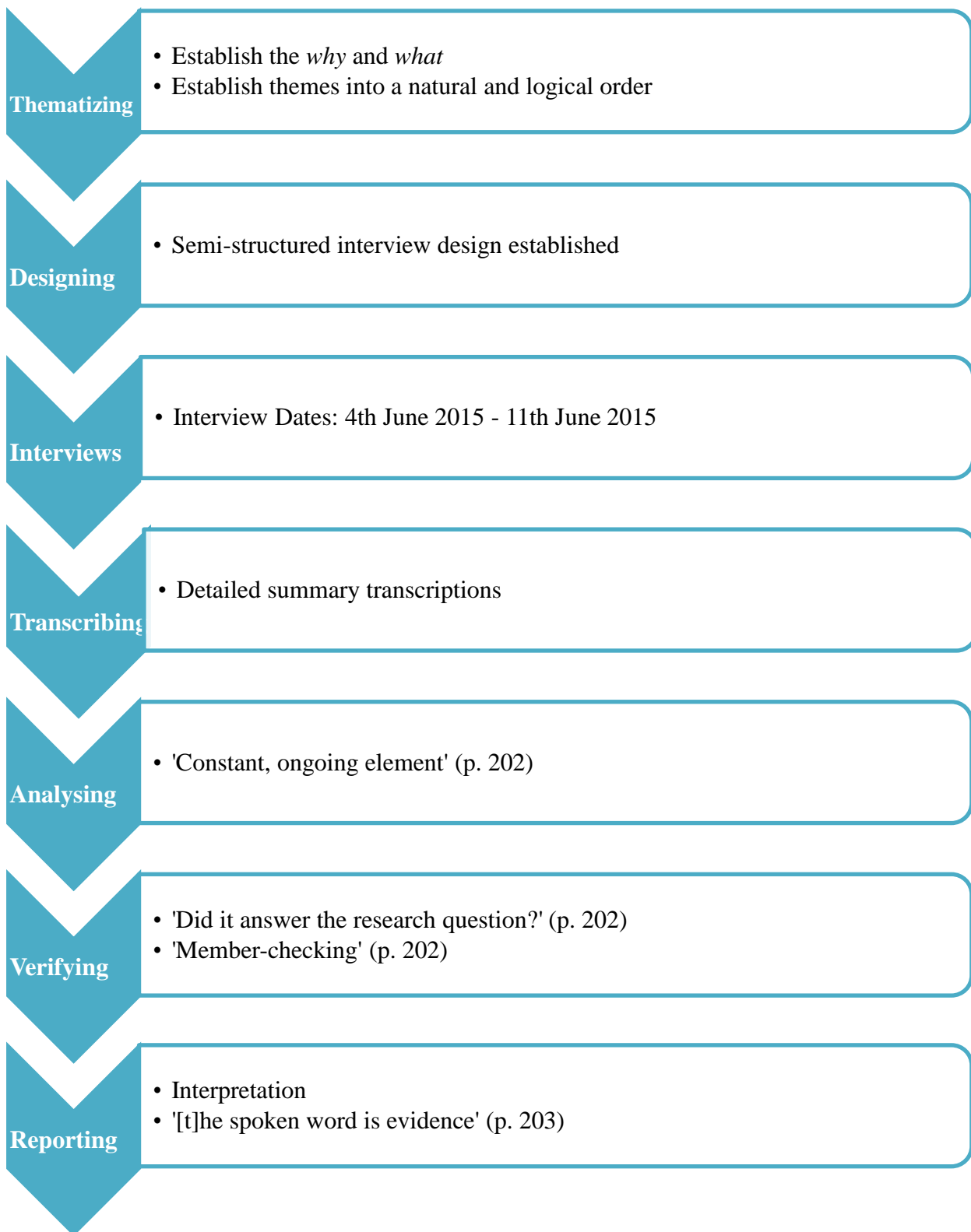
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Appendices

Appendix A – The Interview Process.¹⁴⁰



¹⁴⁰ Please note that the seven stage interview process is referred to in Alison Jane Pickard's *Research Methods in Information*. The diagram is this author's own.
Alison Jane Pickard, *Research Methods in Information* (London: Facet, 2013), pp. 195-206.

Appendix B – Informed Consent Forms

Face-to-face Interviews

Informed Consent Form **Department of Information Studies, *University College London***

Project Title: ‘The Future Will Be Open’: Open Government Data and Recordkeeping in the *National Health Service*

Researcher: Emma Harrison emma.harrison.14@ucl.ac.uk

Thank you for your interest in taking part in this research, which is being carried out as part of the multinational *InterPARES Trust Project* (<http://interparestrust.org/>). The central aim of this project is to consider the role of recordkeeping in the context of new obligations on the *NHS* sector towards Open Government, Open Data and enabling greater information access to citizens.

Participant’s Statement for interview respondents
1 June 2015 – 15 June 2015

- I agree that I will be interviewed for the purposes of data collection in this project.
- I understand that my participation will be audio-recorded and that detailed summary transcriptions will be made and I consent to use of this material as part of the project.
- I understand that I can request a copy of the detailed summary transcriptions and I can correct the detailed summary transcriptions if necessary. Please tick here and provide contact details if you would like to receive the detailed summary transcriptions
-
- I agree that the data collected can be used in any reports and other outputs from the research project and the researcher’s MA report. I understand that the research is part of the multinational *InterPARES Trust Project* (<http://interparestrust.org/>) and the results may be published in, for example, the form of a journal article, and that the text may be made available by the University in its digital repository or in print.
- I understand that respondents will not be individually named but will be referred to by their job title in the above outputs. If you wish for further confidentiality, please indicate here.....
- The data will be collected and stored in accordance with the *Data Protection Act 1998*. It will be retained for the duration of the project and for a period of up to 5 years afterwards in order to allow for re-examination of the data by the researcher or her supervisors, and further publications.
- I understand that participation is voluntary.

Please contact the Archives and Records Management Programme Director, Dr Andrew Flinn, (a.flinn@ucl.ac.uk) at DIS *UCL* if you have any questions or concerns.

Many thanks for your participation.

Name of respondent:

Signature:

Date:

Email Interview

Informed Consent Form
Department of Information Studies, University College London

Project Title: ‘The Future Will Be More Open’: Open Government Data and Recordkeeping in the NHS

Researcher: Emma Harrison emma.harrison.14@ucl.ac.uk

Thank you for your interest in taking part in this research, which is being carried out as part of the multinational InterPARES Trust Project (<http://interparestrust.org/>). The central aim of this project is to consider the role of recordkeeping in the context of new obligations on the NHS sector towards Open Government, Open Data and enabling greater information access to citizens.

Participant’s Statement for interview respondents
July 2015

- I agree that I will participate in an email interview for the purposes of data collection in this project.
- I understand that my typed responses to the questions in the email interview will be retained and I consent to use of this material as part of the project.
- I agree that the data collected can be used in any reports and other outputs from the research project and the researcher’s MA report. I understand that the research is part of the multinational InterPARES Trust Project (<http://interparestrust.org/>) and the results may be published in, for example, the form of a journal article, and that the text may be made available by the University in its digital repository or in print.
- I understand that respondents will not be individually named but will be referred to by their job title in the above outputs. If you wish for further confidentiality, please indicate here.....
- The data will be collected and stored in accordance with the Data Protection Act 1998. It will be retained for the duration of the project and for a period of up to 5 years afterwards in order to allow for re-examination of the data by the researcher or her supervisors, and further publications.
- I understand that participation is voluntary.

Please contact the Archives and Records Management Programme Director, Dr Andrew Flinn, (a.flinn@ucl.ac.uk) at DIS UCL if you have any questions or concerns.

Many thanks for your participation.

Name of respondent:

Signature:

Date:

Appendix C – Interview Schedules

Interview Schedule 1

TNA Senior Advisor, 20 Years Programme (NHS and DEFRA)

Thursday 4th June 2015

Thank you for taking part in this research. The central aim of this project is to consider the role of recordkeeping in the context of new obligations on the NHS sector towards Open Government, Open Data and enabling greater information access to citizens.

[Issue and sign consent form]

1. Role and Responsibilities

- 1.1 Please can you explain your role within TNA and the responsibilities of the department within which you work?
- 1.2 Could you briefly explain a little about your professional background and qualifications?

2. Policies

Publicly available policies [Records Management]

- 2.1 I understand that the NHS *Records Management Code* is currently being revised; how has the publishing of codes such as this affected the health sector?
- 2.2 How do you think the NHS *RM Code* fits in with the Open Government Data agenda in the NHS?
- 2.3 The NHS *RM Code* is supported by material such as the Information Governance Toolkit. What are the benefits and barriers to the self-assessment aspect of this toolkit?
- 2.4 Norway has been heralded by some researchers as a leading example in developing and implementing Open Government Data; the Norwegian government ensure that a document is available for access as soon as possible. In the UK, we have recently seen the newly reduced 20-year closure rule. In what ways could the new 20-year closure rule affect the Open Government Data agenda in the health sector?
- 2.5 The Open Government Data initiative is not currently underpinned by any legislation, in the way that FOI and DP is. Do you think this is an issue?
- 2.6

Internal policies [Open Government Data]

- 2.7 Record transfer reports are available on the TNA website. What internal policies are in place at TNA specifically relating to the publication and management of Open Government Data?
- 2.8 How are these policies (or adherence to these policies) monitored?
- 2.9 Are these policies reviewed? If so, how and when? By whom are they reviewed?
- 2.10 Have Records Managers been involved in the construction and review of the policies and standards?
- 2.11 Do TNA look outwards at international practice to help develop UK policies on Open Government Data? If so, can you give any examples?
- 2.12 What challenges have you experienced in relation to developing policies for the construction and management of Open Government Data?

3. Practice

- 3.1 Does the TNA use a standardised process for creating and applying metadata to Open Government Data?

- 3.2 What are the benefits to using visualisation to present and open up data to the public? For example, the use of graphs to show the records *transferred to TNA* by the Department of Health between 1984 and 2014.
- 3.3 Are there any barriers to using visualisation to present and open up data to the public?
- 3.4 Visualisation is a form of processed data. Can you guarantee traceability back to the raw data source? If so, how?
- 3.5 The NHS *RM Code* talks about the value of ‘high-quality information’. How can you guarantee that Open Government Data at TNA is of a high-quality?
- 3.6 The NHS *RM Code* states that all patient records will be in electronic format in the future, and that the use of an NHS unique identifier number will ‘support the concept of a lifelong record’. The continuing accessibility is identified as the responsibility of the Care Records Service (CRS) and applies to patient (medical) records. Are the same principles regarding longevity being applied to corporate (administrative) records? If so, who is responsible for this?
- 3.7 Who does TNA aim Open Government Data regarding the health sector at? Do you have an average user in mind when publishing Open Government Data?
- 3.8 How is it determined which data should be published? Who determines which data should be published?
- 3.9 What do you think are the benefits of publishing data in the health sector? Do you have any evidence of these benefits?
- 3.10 What do you think are the barriers to publishing health sector data? Do you have any evidence of these barriers?
- 3.11 Are users and/or usage of Open Government Data measured by the TNA?

4. Definitions

- 4.1 How would you define *Open Government Data*?
- 4.2 What do you think is meant by the word *Open*? Does it mean information should be open and useable/able to manipulate, or can it just mean that information should be open and readable?
- 4.3 Do you think there is a difference between the term *Open Government* and the term *Open Government Data*?
- 4.4 Open Government Data is often talked about alongside concepts such as *transparency, accountability* and *governance*. How would you explain the relationship between these different concepts?

5. The Future?

- 5.1 What are the plans for the future in terms of the management of Open Government Data in the health sector?
- 5.2 Are there any other issues you think are important concerning Open Government Data in the health sector?

Thank you for your time. Are there any copies of the internal policies and other documentation that we have discussed that I may be able to access for reference purposes?

Interview Schedule 2
NHS England's Head of Data Policy
Monday 8th June 2015

Thank you for taking part in this research. The central aim of this project is to consider the role of recordkeeping in the context of new obligations on the NHS sector towards Open Government, Open Data and enabling greater information access to citizens.
[Issue and sign consent form]

1. Role and Responsibilities

- 1.1 The NHS England website outlines the work of the Data Policy Unit in three areas: information standards, open data, and care data. Please can you expand upon your role within NHS England and the responsibilities of the department within which you work, specifically relating to open data?
- 1.2 Could you briefly explain a little about your professional background and qualifications?

2 Policies

Publicly available policies [Records Management]

- 2.1 I understand that the NHS *Records Management Code* is currently being revised; how has the publishing of codes such as this affected the health sector?
- 2.2 How do you think the NHS *RM Code* fits in with the Open Government Data agenda in the NHS?
- 2.3 The NHS *RM Code* is supported by material such as the Information Governance Toolkit. What are the benefits and barriers to the self-assessment aspect of this toolkit? Do you think the toolkit has limitations?
- 2.4 The Open Government Data initiative is not currently underpinned by any legislation, in the way that FOI and DP is. Do you think this is an issue?
- 2.5 Another interviewee has commented that the IGT is done without question in the NHS, despite not being mandated by legislation. Do you think there is anything in particular that forces compliance?

Internal/organisational policies [Open Government Data]

- 2.6 The NHS England website explains that the NHS is mandated by government to develop organisational policies around the Open Government Data and transparency agendas? What organisational policies are in place, therefore, in NHS England around these agendas?
- 2.7 How are these policies (or adherence to these policies) monitored?
- 2.8 Are these policies reviewed? If so, how and when? Who reviews these policies?
- 2.9 Have Records Managers been involved in the construction and review of the policies and standards?
- 2.10 Does NHS England look outward at international practice to help develop UK policies? If so, can you give any examples?
- 2.11 What challenges have you experienced in relation to developing policies for the construction and management of Open Government Data?

3 Practice

- 3.1 Is there a standardised process for creating and applying metadata to Open Government Data?
- 3.2 Is it mostly raw data or mostly processed data that is published?

- 3.3 If processed data is published, can you guarantee traceability back to the raw data?
- 3.4 The NHS *RM Code* talks about the value of ‘high-quality information’. How can you guarantee that Open Government Data is of a high-quality?
- 3.5 The NHS *RM Code* states that all patient records will be in electronic format in the future, and that the use of an NHS unique identifier number will ‘support the concept of a lifelong record’. The continuing accessibility is identified as the responsibility of the Care Records Service (CRS) and applies to patient (medical) records. Are the same principles regarding longevity being applied to corporate (administrative) records? If so, who is responsible for this?
- 3.6 Who is the Open Government Data aimed at? Do you have an average user in mind when publishing Open Government Data?
- 3.7 How is it determined which data should be published? Who determines which data should be published?
- 3.8 Are users and/or usage of Open Government Data in the NHS monitored?
- 3.9 What do you think are the benefits of publishing data in the NHS? Do you have any evidence of these benefits?
- 3.10 What do you think are the barriers to publishing data in the NHS? Do you have any evidence of these barriers?

4 Definitions

- 4.1 How would you define *Open Government Data*?
- 4.2 What do you think is meant by the word *Open*? Does it mean information should be open and useable/able to manipulate, or can it just mean that information should be open and readable?
- 4.3 Do you think there is a difference between the term *Open Government Data* and the term *Open Government*?
- 4.4 Open Government Data is often talked about alongside concepts such as *transparency, accountability* and *governance*. How would you explain the relationship between these different concepts?

5 The Future?

- 5.1 What are the plans for the future in terms of the management of Open Government Data in the health sector?
- 5.2 Are there any other issues you think are important concerning Open Government Data in the health sector?

Thank you for your time. Are there any copies of the internal policies and other documentation that we have discussed that I may be able to access for reference purposes?

Interview Schedule 3

NHS England's Senior Data Sharing and Privacy Specialist

Monday 15th June 2015

Thank you for taking part in this research. The central aim of this project is to consider the role of recordkeeping in the context of new obligations on the NHS sector towards Open Government, Open Data and enabling greater information access to citizens.

[Issue and sign consent form]

1. Role and Responsibilities

- 1.1 Please can you give an overview of your role within NHS England and the responsibilities of the department within which you work, specifically relating to open data?
- 1.2 Could you briefly explain a little about your professional background and qualifications?
- 1.3 Are there up-to-date structural hierarchies that I as a researcher can access? Online documentation appears to refer to the old structure.

2. Policies

Publicly available policies [Records Management]

- 2.1 I understand that the NHS *Records Management Code* is currently being revised; how has the publishing of codes such as this affected the health sector?
- 2.2 Do you think the NHS *RM Code*, or even Records Management in general, fits in with the Open Government Data agenda in the NHS?
- 2.3 Where does the Records Manager fit in with the Open Government Data agenda? How is the role of the Records Manager in the NHS affected by Open Government Data?
- 2.4 The NHS *RM Code* is supported by material such as the Information Governance Toolkit. What are the benefits and barriers to the self-assessment aspect of this toolkit? Do you think there are limitations to the IGT?
- 2.5 The Open Government Data initiative is not currently underpinned by any legislation, in the way that FOI and DP is. Do you think this is an issue?
- 2.6 Another interviewee has commented that the IGT is done without question in the NHS, despite not being mandated by legislation. Do you think there is anything in particular that forces compliance?

Internal/organisational policies [Open Government Data]

- 2.7 The NHS England website explains that the NHS is mandated by government to develop organisational policies around the Open Government Data and transparency agendas? What organisational policies are in place, therefore, in NHS England around these agendas?
- 2.8 How are these policies (or adherence to these policies) monitored?
- 2.9 Are these policies reviewed? If so, how and when? Who reviews these policies?
- 2.10 Have Records Managers been involved in the construction and review of the policies and standards?
- 2.11 Does NHS England look outward at international policies and practice to help develop its own policies and practice? If so, can you give any examples?

3. Practice

- 3.1 Is there a standardised process for creating and applying metadata to Open Government Data?
- 3.2 Is it mostly raw data or mostly processed data that is published?
- 3.3 If processed data is published, can you guarantee traceability back to the raw data?
- 3.4 The NHS *RM Code* states that all patient records will be in electronic format in the future, and that the use of an NHS unique identifier number will 'support the concept of a lifelong record'. Are the same principles regarding continued accessibility being applied to corporate (administrative) records? If so, who is responsible for this?
- 3.5 Who is the Open Government Data aimed at? Do you have an average user in mind when publishing Open Government Data?
- 3.6 Are users and/or usage of Open Government Data in the NHS monitored?
- 3.7 How is it determined which data should be published? Who determines which data should be published?
- 3.8 What do you think are the benefits of publishing data in the NHS? Do you have any evidence of these benefits?
- 3.9 What do you think are the barriers to publishing data in the NHS? Do you have any evidence of these barriers?

4. Definitions

- 4.1 Do you think there is a difference between the terms *Open Data*, *Open Government Data* and the term *Open Government*?
- 4.2 What do you think is meant by the word *Open*? Does it mean information should be open and useable/able to manipulate, or can it just mean that information should be open and readable?
- 4.3 Open Government Data is often talked about alongside concepts such as *transparency*, *accountability* and *governance*. How would you explain the relationship between these different concepts?

5. The Future?

- 5.1 What would you like to see in the future in terms of the management of Open Government Data in the health sector?
- 5.2 Can you see open data replacing FOI at all, or making FOI redundant, as one Government Minister has suggested?
- 5.3 Are there any other issues you think are important concerning Open Government Data in the health sector?

Thank you for your time. Are there any copies of the internal policies or other documentation that we have discussed that I may be able to access for reference purposes?

Interview Schedule 4
HSCIC Senior Information Governance Advisor
Email Interview July 2015

Thank you for taking part in this research. The central aim of this project is to consider the role of recordkeeping in the context of new obligations on the NHS sector towards Open Government, Open Data and enabling greater information access to citizens.

Please remember to sign the consent form.

Please type your responses below each separate question. If the question appears unclear, then you can ask for further clarification.

1. Role and Responsibilities

- 1.1 Please can you give an overview of your role within HSCIC and the responsibilities of the department within which you work?
- 1.2 Are there organisational hierarchies available for the HSCIC that demonstrate the position of the department within which you work in relation to the rest of the organisation?
- 1.3 The HSCIC is described as ‘an executive non-departmental public body’. Could you explain more about the HSCIC’s relationship to Government and to NHS England?
- 1.4 Could you briefly explain a little about your professional background and qualifications?

2. Policies

Publicly available policies, guidance and toolkits

- 2.1 The NHS Records Management Code is supported by material such as the Information Governance Toolkit. What are the benefits and barriers to the self-assessment aspect of this toolkit?
- 2.2 Another interviewee has commented that the Information Governance Toolkit is done without question in the NHS, despite not being mandated by legislation. Do you think there is anything in particular that forces compliance?
- 2.3 The Open Government Data initiative is not currently underpinned by any legislation, in the way that FOI and DP is. Do you think this is an issue?

Internal/organisational policies

- 2.4 What organisational policies are in place at HSCIC around Open Data and the publishing of health sector information for re-use by the HSCIC?
- 2.5 How are these policies (or adherence to these policies) monitored?
- 2.6 Are these policies reviewed? If so, how and when? Who reviews these policies?
- 2.7 Have Records Managers been involved in the construction and review of the policies and standards?
- 2.8 Does HSCIC look outward at international practice to help develop their policies? If so, can you give any examples?
- 2.9 What challenges have you experienced in relation to developing policies for the construction and management of Open Government Data at HSCIC?

3. Practice

- 3.1 Is there a standardised process for creating and applying metadata to Open Government Data at HSCIC?
- 3.2 Is it mostly raw data or mostly processed data that is published?

- 3.3 If processed data is published, can you guarantee traceability back to the raw data?
- 3.4 How specifically does HSCIC help ‘health and care organisations improve the quality of the data they collect and send’ to HSCIC?
- 3.5 Who is the Open Government Data aimed at? Do you have an average user in mind when publishing Open Government Data?
- 3.6 How is it determined which data should be published? Who determines which data should be published?
- 3.7 Are users and/or usage of Open Government Data monitored?
- 3.8 Attention has recently been given to the sharing of data at HSCIC. How do you think the reporting of such issues in the national media impacts the Open Government Data agenda?
- 3.9 What do you think are the benefits of publishing health sector information for re-use? Do you have any evidence of these benefits?
- 3.10 What do you think are the barriers to publishing data in the health sector for re-use? Do you have any evidence of these barriers?

4. Definitions

- 4.1 What do you think are the key formal elements, attributes, and nature of Open Government Data?
- 4.2 What do you think is meant by the word *open*? Does it mean information should be open and useable/able to manipulate, or can it just mean that information should be open and readable?
- 4.3 Do you think there is a difference between the terms *Open Government Data*, *Open Data* and *Open Government*?
- 4.4 Open government data is often talked about alongside concepts such as *accountability* and *governance*. How would you explain the relationship between these different concepts?
- 4.5 *Transparency* is inevitably mentioned alongside *Open Data* on the HSCIC website. Is this relationship between these two concepts specific to the NHS? Could you explain more about this relationship?

5. The Future?

- 5.1 What are the plans for the future in terms of the management of Open Government Data at HSCIC?
- 5.2 How would you personally like to see open government data progress in the future?
- 5.3 What do you think to the suggestion by a Cabinet Minister that Open Data will replace FOI, making the latter ‘redundant’?

6. Plenary

- 6.1 Are there any other issues you think are important to raise concerning Open Government Data in the health sector and at HSCIC?

Thank you for your time.

Appendix D – Detailed Summary Transcriptions of Interviews

Detailed Summary Transcription 1

TNA Senior Advisor, 20 Years Programme (NHS and DEFRA)

Thursday 4th June 2015

Time (minutes : seconds)	Question	Summary	Keywords
00:20	1.1	Role is 'quite narrow', mostly specifically in relation to the transition to a 20-year rule in respect of the NHS and certain other bodies. May have wider implications too though. Working within Archive Sector Development (ASD) department, a department that works closely with the wider archive sector.	Role; responsibility; department; TNA
01:53	1.2	History degree, archive qualification. Most of career spent in local government, across both archives and Records Management. Been at TNA since 2005, with ASD.	Professional background; qualifications; history degree; archive qualification; local government
02:44	2.1	NHS <i>RM Code</i> currently being reviewed. Updated as 'a matter of practice'. Code 'only appeared in 2006', 'similar guidelines provided through a series of health service circulars', earliest in about 1961. <u>During the transcript verification stage, the participant added the following:</u> 'The NHS RM Code is, I think, technically issued under powers contained in s.265 of the <i>Health and Social Care Act 2012</i> : http://www.legislation.gov.uk/ukpga/2012/7/part/9/chapter/2 and specifically subsection 5: <i>A health or social care body to whom advice or guidance is given under this section must have regard to the advice or guidance in exercising functions in connection with the provision of health services or of adult social care in England. .</i> Although in practice, similar guidance has been provided by the SoS since 1961 (at least), though probably on a different statutory basis (successive Health or NHS Acts)'.	NHS <i>RM Code</i> ; review

04:00	2.1	Similar question asked in terms of the signing off of the current version of the reviewed code. Code is seen as, 'guidance to which NHS organisations have to take account of, [...] so that's not to say they absolutely have to do exactly what it says but they have to have looked at it and decided "I'm not going to do that because there's some particular factor why I shouldn't". That's my understanding of it'.	NHS <i>RM Code</i> ; non-mandatory guidance
04:42	2.1	Structure of NHS has changed. Implementation of the <i>PRA</i> applies to England and Wales, but 'Welsh one effectively is autonomous', as they are responsible to the Welsh Government. England and Wales still work closely, but they are distinct. 'Two NHSs'.	Structure; NHS; <i>PRA</i> ; England; Wales
06:00	2.2	IGT not solely linked into the NHS <i>RM Code</i> . Other guidance also relevant, including confidentiality guidance. Focus on patient confidentiality and information sharing. Opinions about the toolkit are mixed; it is 'felt to be useful' but it 'has its limitations'. Latest revision just out (version 13). IGT not really within the interviewee's remit as it is not done by TNA [it is created and published by HSCIC].	IGT; NHS <i>RM Code</i>
09:03	2.3	Open Government Data initiative and the NHS <i>RM Code</i> are 'probably slightly different areas'. Interviewee's own observation is that 'the two are not hugely linked'. 'Absolute laser focus of the NHS tends to be in terms of patient information'. 'Very much <i>DPA</i> first, and the associated issues of privacy'. 'A lot of the stuff in the Code revolves around that'. NHS <i>RM Code</i> relates to issues of patient recordkeeping, addressing issues such as gender recognition in patient records. Open Government Data is not the focus of the Code, although 'these things will have some impact'.	Open Government Data; NHS <i>RM Code</i> ; patient information; patient recordkeeping; <i>DPA</i>
12:02	2.4	20-year closure rule and Open Government Data have 'come from slightly different directions, although obviously they are linked'. 'The distinction is between proactive publication of information as opposed to continued access'. ' <i>PRA</i> is driven by <i>FOIA</i> , so largely a demand-led thing'. Not a 'direct linkage', but interviewee agrees that there is a 'general move to open things up a lot more than was the case before'.	20-year closure rule; proactive publication; continued accessibility; <i>PRA</i> ; <i>FOIA</i>

13:45	2.5	The IG function within the NHS 'quite well-developed', with regional groups. Statutory support 'always makes a difference', but 'the IGT is not directly mandated by legislation but it is [...] done without question'. TNA, as a result, are trying to include requirements on the 20-year rule implementation into the toolkit, as it is something the NHS 'just does'.	IG; 20-year closure rule; compliance; IGT
17:08	2.6	Interviewee did not know if a formal policy document existed for the release of information relating to Record Transfer Reports, although it was 'clear from the start' that information would be released relating to the progress of the transfers. In terms of publishing the RTR there has always been a clear vision.	Policy; formal documentation; vision; Records Transfer Reports
21:20	2.11	Information Policy department more focused on Open Data.	Information Policy department; open data
22:11	2. 10	'Not a huge amount' of consideration given to international practice in relation to the interviewee's role and responsibilities as 'it's so very tightly tied into the particular piece of legislation'. Regarding the NHS <i>RM Code</i> , there has been engagement with Scotland, Northern Ireland and the Republic of Ireland, due to overlaps. Occasional contact with colleagues in the States and Australia. Interviewee's role is 'quite legislation specific'.	International practice; legislation; Scotland; Northern Ireland; Republic of Ireland; the States; Australia

25:30	3.6	<p>There is a difference between the concern for patient/medical records and corporate/administrative records, with Patient Records Manager roles in most organisations/trusts but not a Corporate Records Manager role. Barts Health has a corporate records function, however. In Trusts, the Patient Records Manager typically branches out or has responsibility for corporate records 'dumped on them' sometimes. Decentralised process for administrative records. This difference in emphasis between medical and corporate records is 'entirely understandable', as it is literally a matter of life and death in the NHS. With resource issues in mind, patient information is the 'priority area'.</p>	<p>Patient records; medical records; corporate records; administrative records</p>
29:56	3.6	<p>Issues of continued accessibility are, 'in general at an early stage'. Interviewee is working with 'very much paper, or at best hybrid' records with the 20-year closure period. Migration issue is not yet 'critical', although 'that certainly is arising with some NHS trusts'. 'I don't think these things have been around for long enough for people to really start thinking about that'. TNA looking at adding migration guidance into the NHS <i>RM Code</i>, especially how to manage electronic records. Still a lot of work left to do with regards to migration. Interviewee cannot see prioritisation of patient records changing with digital continuity. Interviewee gives example of the Jimmy Saville scandal in making people 'think about that [continued accessibility] a little bit more'; recommendation in a report included the NHS looking again at maintaining records for 'maintaining accountability'. Reports make a link between the care of records and accountability, as there were difficulties in the case in even trying to access 'basic information', including who was working at the trusts at the time. 'It's not news to archivists that the focus tends to be on the last 10 minutes'.</p>	<p>Continued accessibility; paper records; hybrid systems; digital continuity</p>
34:48	3.7	<p>Not sure there is 'a conscious aim' in targeting information towards an average user, although TNA are aware that the information has been picked up by, for example, national media. Beyond that, there is not really 'a fixed audience in mind, although that will vary depending on the information'.</p>	<p>Users; national media; fixed audience</p>

36:35	3.7	'Close eye' kept on the usage of TNA website, including dwell times, and where people are coming from to get to the website. 'Very conscious that the website is a major public service delivery channel, so we keep a close eye on that'.	Usage; website
38:06	3.8	Decisions regarding what data should be published probably coming from Information Policy and the Chief Executives. 'Pretty good data' kept in comparison to other institutions, for example national museums. <u>During the transcript verification stage, the participant added the following:</u> 'Something specific to TNA is that there is perhaps a distinction to be made between the pro-active publication of our own corporate information, and that of historical government records in our custody, which is mainly driven by a different department. But in both cases, we certainly use public feedback to inform what goes up: for example, we responded to media enquiries on the Records Transfer Report for 20YR by gathering and providing some additional information, while on digitisation of records, we have a constantly updated 'top 10' of records series demanded on site, and also maintain links with specialist potential markets'.	Publication of data; monitoring usage
41:07	3.9	Benefits of Open Government Data relate to maintaining accountability in the NHS, an issue which has received attention since the Jimmy Saville reports. TNA now more conscious of maintaining accountability, also similar issues seen in the Hillsborough case. Interviewee interested in 'potential benefits from the NHS learning from past experience'. NHS 'clearly under increasing levels of scrutiny'.	Maintaining accountability; Jimmy Saville reports; Hillsborough case
44:45	3. 10	Referring to the publication of NHS information via the HSCIC: 'A lot of the data that is available is centrally mandated', leading to resource issues, including duplication of effort. With regards to the 20-year-rule, there are processes in place to try and avoid a duplication of effort. 'Managing records in the transition period will be quite a challenge for the NHS', with double the amount of processing levels which will be 'tough to manage'. TNA are providing additional training to help, and also facilitating contacts with places of deposit too. Resource issue is 'an important one'.	Resource issues

47:51	4.1	Focus of Open Government Data is on the following questions: 'What information can most usefully be published'? What form is most useful to the people that want to use it?	Focus; publication; format
49:04	4.2	Government policy has consistently been to [...] make stuff re-useable [...] quite an emphasis on that'. Overlap of transparency v. re-use, with the latter for economic reasons. The two are best thought of in a Venn Diagram, 'if material is extensively re-used it is also more visible and potentially more transparent because stuff which perhaps isn't in its raw form isn't particularly easy to get to grips with can be developed into something which is'. Transparency and re-use are 'not in opposition with one another', but they are 'different motivations'.	Government policy; transparency; re-use; open
51:06	4.4	When thinking about terms such as <i>accountability</i> , <i>transparency</i> and <i>governance</i> , there is a danger of 'imposing slightly more rigid boundaries on the policy space than is justified'. There are different areas of focus with regards to these terms, but they 'are generally perceived as being mutually supporting'.	Definitions; accountability; transparency; governance; boundaries
54:06	5.1	'Fairly well-accepted' in the NHS IG area that it will 'generally be feasible for people to get access to information and to re-use it, with the very obvious caveat in relation to patient information'. NHS seems 'reasonably comfortable' with this idea for the future.	Information Governance; access; re-use
55:15	5.1	'Too early' to comment on whether FOI may be replaced by Open Government Data. Interviewee is unaware of any comments or statements of this nature in public policies; 'early days in the new administration'. There have been similar discussions in various foreign administrations, 'there can sometimes be a certain amount of grey area in terms of is open data the same as FOI, or is one being portrayed as the other?'. 'They are clearly related but not the same thing'. 20-year rule links back to Labour leadership and Gordon Brown, although picked up by subsequent governments too: There is a 'difference in emphasis but I get the impression that there is a certain degree of consensus around a lot of these things. I would be surprised if there were major changes'.	FOI; Open Government Data; definitions

57:51	5.2	<p>‘One of the issues going forward is this question of, from our perspective, of how we will be able to maintain the publicly accessible [...] data over the longer term’. Websites are particularly complicated and 'difficult to manage'. Interviewee's focus is up to 2004 with the 20-year rule so have 'very consciously parked the digital preservation issue to some extent because we have to manage things in bite size chunks'. Intention to use the NHS <i>RM Code</i> to 'nudge things in a direction which makes it easier, but will have to see how that pans out'.</p>	<p>Maintaining accessibility; website management; NHS <i>RM Code</i></p>
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Detailed Summary Transcription 2
NHS England's Head of Data Policy
Monday 8th June 2015

Time (minutes: seconds)	Question	Summary	Keywords
00:30	1.1	Interviewer refers to the NHS England website which states three areas of work for the Data Policy Unit, though the interviewee states that information standards are not within their professional remit.	NHS England; Data Policy Unit; role; responsibilities
00:47	1.1	Up until 2 February 2015, interviewee was the Head of Open Data and Transparency for NHS England. An 'organisational restructure' has resulted in a move to the role of Head of Data Policy. The current role is much 'wider', but still with a 'very strong interest and focus on Open Data and transparency'.	Structure; Head of Data Policy; open data; transparency; role; responsibility
01:15	1.1; 2.10	The Data Policy Unit is 'still forming' with 'disparate projects', but the 'aim' is to 'eventually become almost an internal consultancy or think-tank for NHS England where we start to really build an evidence-based policy-making approach with regards to the information content of policies'. There is also a 'remit to learn from the best across the UK and internationally'.	Data Policy Unit; remit; role
02:01	1.1	Unknown whether parallel departments exist in Wales or Scotland, although 'probably should know and probably should have strong links with them'. Presumption that Scotland would 'almost certainly' have a similar unit due to their focus on transparency, and expected that Wales would have the responsibilities within someone's professional remit.	Wales; Scotland; transparency
02:28	1.2	Qualifications include 2 Law degrees, including BA and MA. Professional background includes roles as an analyst in healthcare regulation, a commissioner in a primary care trust, and a product owner/curator for comparative information on <i>NHS Choices</i> website.	Qualifications; professional background; law

04:24	2.1	Interviewee 'not particularly close to the <i>RM Code</i> at all', which 'sits elsewhere'. 'Codes like that matter to a very small number of people'. 'Vast majority are unaware' of such codes; NHS 'pump out a vast amount of documentation'. 'Each one [code] fits in with an incredibly small audience'.	NHS <i>RM Code</i>
04:56	2.2	Interviewee agrees that the <i>RM Code</i> should fit in with the Open Data agenda. Personal view is that the 'principles of transparency and the mechanisms of open data should be enshrined in all of your data products', which can include guidance documentation, setting up a new data collection, defining a new analysis, etc. Link made between transparency and 'publicly funded data'. Open Data is not just publishing a product, but also about being transparent about the process e.g. publishing governance structures and minutes, publishing detailed methodologies, result of reviews and evaluations, etc. Interviewee agrees that there is the potential to link up the <i>RM Code</i> with an Open Government Data agenda. Link already seen in other documentation: <i>Statistical Code of Conduct</i> 'absolutely shrines transparency within it and you would expect Records Management codes of conduct to do the same thing'.	NHS <i>RM Code</i> ; open data agenda; <i>Statistical Code of Conduct</i>
06:45	2.5	N3 connectivity forces compliance with the IGT; 'cannot do business with or as the NHS if you are not N3 compliant', and the IGT is a prerequisite of N3 connectivity. N3 is a 'necessity', a form of internal internet and it provides, amongst other services, 'secure email'; N3 is 'entirely sectioned off from the main internet'.	N3; IGT

07:57	2.3	Interviewee raises a particular issue with the IGT and IG: 'Information governance has been almost boiled down to nothing but security and privacy, whereas eight years ago it was much wider than that and it encompassed things like data quality and wider aspects of Records Management as well as security and privacy'. IGT toolkit has 'played a part in narrowing that down'. Now there is a 'focus on the technical aspects rather than the wider ethical implications of IG'. Exposure of scandals relating to the NHS in national media appeared after this narrowing had already begun, so have not caused the narrowing. Interviewee would like to see IG 'pulling back a bit to that wider and broader, more holistic, view'.	IGT; IG; narrowing of IG
09:52	2.6	Organisational policies centred on Open Government Data and transparency agendas are 'fairly limited'. Head of Data Policy has not written any policies on these agendas. 'Policies go into a dusty place. They tend to be too large and utterly impenetrable'. There is a need for a 'simpler way of doing business'. No single transparency document exists, but the 'big, national policy documents have absolutely got it enshrined in them', due to a higher-level recognition of the transparency agenda. A case of 'building them in rather than creating something separate and different'. Examples include the <i>Five Year Forward View</i> , and the National Information Board, which 'absolutely enshrine transparency'.	Organisational policies
11:25	2.7	Policies monitored by 'different mechanisms', including 'various programme boards for the individual strands of work', and an example includes exchange of information about Open Data and transparency with Clinical Audits Team, 'on a regular basis'.	Monitoring; policies

12:34	2.8	<p>Due to structural changes, the organisation is still very new and, thus, the majority of policies are 'not over 2 years old yet'. 'We don't have specific Open Data and transparency policies. We do embed them within these wider streams of work'. Some of the policy documents are not in the usual policy form, or the usual form of a "How To" guide. Example includes 'the <i>Five Year Forward View</i> which is a big strategic document', which would probably not be refreshed every 2 years, as with other policies. <i>How To</i> policies in NHS England 'likely to have a 2 year review cycle'.</p>	Reviewing; policies
13:30	2.6	<p>Open Data and transparency is 'not something somebody over here does in a little box and it is not something somebody goes and pulls out a "How To" guide on. It's something that you build into work that already goes on'. Agendas are not separated from work. This embedded approach helps to make it 'part of the mainstream', and is an attempt to help people to 'think differently', rather than handing them a policy with "How To" guidance.</p>	Open data; transparency; agendas embedded; agendas enshrined
14:55	2.9	<p>Head of Data Policy influences the embedding of Open Data and transparency agendas in wider policies: 'you don't have to write a policy to influence a policy'. Data Policy Unit participates in drafting processes. Transparency champions also influential, including Tim Kelsey [National Director for Patients and Information]. 'Strong series of allies across the board', including Bruce Keogh who is 'an absolute champion of transparency'.</p>	Influencing policies

15:46	2.11	<p>Barriers include cultural change issues; nervousness exists, especially regarding the use of the data by the press. There is a lack of understanding regarding terminology, especially the term 'Open Data', which some people believe refers to the opening up of personal data, 'which of course it absolutely can't be'. Others believe Open Data is an 'attempt to create league tables'. There is also a lack of confidence in the data being used. This means there is a need for conversations with others: 'Is this FOI-able, if so we should be proactively publishing it' type-of conversation. Also need reassurance and confidence-building around the press, including 'acceptance' and 'mitigation' of 'unhelpful behaviour by the press'. 'We are not as a nation yet very mature about Open Data', which is also the same with other nations. 'Witch-hunt' first, looking for the 'worst'; there is a need 'to get over that and carry on'.</p>	<p>Barriers to policies; terminology; misunderstanding; lack of confidence; immaturity</p>
17:49	2.11	<p>Head of Data Policy helps people to understand that 'the more they put into the publication the better'; more supporting information will help to reduce the data being used 'irresponsibly'. Also need to find those people who will 'remain involved' beyond publication. NHS, as with other industries, 'is awful for just dumping data and leaving it', but further support is also needed e.g. people will need support in using the data.</p>	<p>Understanding; supporting information; post-publication support</p>
18:55	3.1	<p>Metadata processes 'depend on the nature of the data'. Standardised, 'approved' and 'strict' processes for national and official statistics. Otherwise, 'not really' a standardised process but more an encouragement of 'good practice', including tick boxes or 'formulaic lists', covering, for example, date ranges and data sources. Also 'softer' guidance around 'quality and utility of data which can be done to a greater or lesser extent'.</p>	<p>Metadata; standardised processes; guidance</p>

19:58	3.1	NHS England now has a data catalogue, built on the same technology as data.gov.uk, to 'demonstrate to the world the information that NHS England is using and making that information available for re-use'. A key functionality turned off on data.gov.uk version which has remained on in the NHS version is an integrated API [interface functionality].	Data catalogue
21:08	3.2	Mostly processed data published by NHS England, although some 'outcomes as well', including 'mortality and morbidity information'.	Processed data
21:29	3.3	Individual items 'should say what data it was that they used in the production'. Full data files not necessarily published due to personal/identifiable information, for example cancer waiting times, so best practice is to 'reference the submission and publish the summary file'.	Traceability; raw source; processed data
22:22	3.5	Regarding the target of fully-electronic records by 2018, there are 'different definitions of the target'. The target is about the capability of interfacing systems; there is a focus on interoperability. 'Significant shift' towards electronic records evident. Should have made 'significant steps towards' the target by 2018, although probably not completely 100% electronic.	Electronic records; interoperability; interfacing systems
24:22	3.5	Cannot really 'divorce administrative and clinical' records so neatly. It is a historical distinction that has prevented people from taking 'proper ownership of the electronic records'.	Administrative records; clinical records; distinction

25:56	3.6	<p>There is 'not really' an average user in mind when data is published by NHS England. Open Data 'aimed at a relatively technical audience', including 'developer-type audience and analyst-type audience'. Variety of formats, including portals specifically for the public. 'Primary publications are often quite technical', with re-publications 'tailored a little bit more to audience'. 'Re-use in earnest' includes a 'few main groups', including developers and analysts, 'super engaged patients', including charity activists and health-watch members. 'Patchy' mix of users, with groups of 'incredibly enthused' people and others 'who are completely blind to it and run screaming to the hills'. Organisations also use the data, including Dr Foster.</p>	Users; average user; audience; re-use
27:43	3.8; 2.9	<p>Unable to '100% monitor what is going on and you shouldn't. It's not the point of Open Data'. NHS England regularly 'cast a net out' to evaluate impact. 'Re-use isn't as good as we would like to see it', for example prescription data 'doesn't get a huge amount of re-use'. Open data is 'not translating into the sorts of benefits that we would like to see yet'.</p>	Monitoring users; evaluate impact; re-use levels; benefits
28:30	3.8	<p>Number of possible reasons for low levels of re-use: information is often put out in a 'clunky' way, often using spreadsheets. Data is not published in a 'particularly efficient way'. Data catalogue aims to make information much easier to re-use. Also, data is not published in a 'very modern way'; there is still a tendency to publish 'big-bang, old-school, vanity style publications, with pretty pictures and big PDF documents, rather than the primary publication being the data itself and other things being a re-use of it'. No encouragement of re-use because there is a focus on a 'crafted publication', rather than 'a re-usable publication'. Head of Data Policy pushes for a change in thinking, with a focus on re-use. NHS (not just NHS England) also criticised for delay in publication; Open Data is 6-9 months old at time of publication. Health-watch 'able to get much better information directly from organisations'.</p>	Re-use levels; information presentation; inefficiency; delays in publication

31:00	3.7	Provisions in place for 'things that have to be published'. Otherwise 'needs-based' and 'dependent on the datasets'. It varies as to who makes the decisions about which data should be proactively published.	Decisions on publication
32:54	3.9	Benefits of Open Data in the NHS are the same as anywhere else, including: 'building public confidence', 'creating efficiency by highlighting variation in either cost or quality', 'reducing corruption, not that there's a huge amount in the NHS', 'keeping people honest', and 'enabling people to help you find solutions'.	Benefits; open data; public confidence; efficiency; corruption; honesty; solutions
33:40	3.9	Interviewee gives example of how Open Data can enable people to find solutions: Obesity data challenge launched in the States, with the aim of making 'developer and analyst communities out there think about obesity in new ways'. Data 'does nothing more than say how obese each nation is', but the aim is for others to correlate this information with other datasets to 'think a bit more creatively about the data they are looking at'.	Benefits; solutions; obesity data challenge
34:45	3.9	Considering evidence of these benefits is 'complicated' and depends on definitions of Open Data; are we defining Open Data as in a re-useable format, published under the Open Government licence, or are we talking about transparency? There is evidence that the public confidence benefit is being fulfilled. People find information published on <i>NHS Choices</i> 'helpful', not for choices but for 'reassurance that somebody is monitoring what is going on'. 'Very poor evidence base for both technology and data in the NHS because people don't systematically review and publish in a high-quality way'.	Benefits; evidence; public confidence

36:40	3.9	<p>Interviewee brings up the following: NHS England commissioned a company called the Governance Laboratory (New York University) to 'review where the NHS is up to with Open data and what the opportunities may be'. Part of this project included the development of a 'straw man, blueprint for evaluating the impact'. This blueprint goes from the point the decision is made to publish, right through to use and re-use. Aim of this blueprint was to build evidence 'much, much quicker' by all using the 'same terminology and a similar and consistent framework'. Also about 'raising the profile of the need for evidence. We expect medicine to act in an evidence-based way, and the same approach should be taken to data information policy'. Research is open on the thegovlab.org/nhs.</p>	<p>Governance Laboratory; review of open data; evaluation; impact</p>
38:40	3. 10	<p>Barriers to Open Data include a 'cultural aspect', which can be made up of 'fear', or is because it is 'the way things have always been done', or even because of 'perceived technical barriers'. There is a need for a 'culture change' and to make people think 'much earlier in the process' about whether practice would 'stand up to external scrutiny'. 'If we can't publish the data itself, what about the data can we publish?', including publishing 'detailed methodologies for peer-reviews and scrutiny, and for further replication'.</p>	<p>Barriers; cultural aspect; cultural change</p>
41:02	4.1	<p>There is disagreement with regards to definitions 'across the world', which is a topic for a report even on its own. A 'tight' definition for the UK is 'things published under the Open Government licence'. A more 'relaxed' and 'wider' definition, advocated by the Head of Data Policy, is 'data which is put into the public domain with little or no restriction on the use of that data'. The different definitions are all part of a 'continuum' and even big organisations 'fundamentally disagree about definitions'. Too tight a definition can prevent people from 'adhering to the spirit' of Open Data, as a strict definition can be 'scary'. Head of Data Policy thinks about the definition as 'transparency with open data as a sub-set'.</p>	<p>Definitions; tight v. relaxed; restrictions</p>

43:11	4.2	With regards to the word 'Open', Head of Data Policy would 'like there to be an emphasis on re-use but it shouldn't be seen as a barrier to releasing information'. Release of information should be encouraged, then working towards a point where the information is 'genuinely open'. Re-use should be encouraged, but there should not be a 'binary yes/no' to the question of what 'Open' means.	Open; re-use; definitions
44:00	4.4	For the interviewee, 'Open Data is one of many facets of transparency'. Transparency is the 'ethos that underpins governance of organisations', a 'principle' which should be 'enshrined in governance structures and Open Data is a mechanism for doing this'	Open Data; transparency; ethos
44:58	5.1	Head of Data Policy would like to see a more 'grown-up approach to the thinking in relation to the publication of data', including publishing 'fully Open Data as default', with the primary publication being 'a high quality, re-useable dataset with appropriate supporting information', with 'the pretty things that people do becoming a re-publication'. Would also wish to see a move away from the public sector continually thinking about 'PDF reports or new websites', and thinking more about a 'high quality primary publication'.	Future; Open Data; maturity
46:18	5.2	More can be done in terms of closed data sets; can still be transparent about the closed data sets by 'producing statistical summary descriptions, and proper statements of quality and utility that relate to them'. This is 'quite important for public trust', to 'help people to see exactly what data we hold'. Would also include summary descriptions from those who have been granted access to the data, including how they used it, to 'enable people to learn from it'.	Closed data sets; transparency
48:44	5:2	Relevant documentation includes the <i>Five Year Forward View</i> and <i>Health Care 2020</i> , which are 'driving almost everything we do right now'. NHS England data catalogue at data.england.nhs.uk . Obesity data challenge at the Rewired State website.	Documentation; <i>Five Year Forward View</i> ; <i>Health Care 2020</i> ; data catalogue; obesity data challenge

Detailed Summary Transcription 3
NHS England's Senior Data Sharing and Privacy Specialist
Monday 15th June 2015

Time (minutes: seconds)	Question	Summary	Keywords
Track 1:			
00:15	1.1	NHS England is a 'statutory body set up by the <i>Health and Social Care Act 2012</i> '. There is a Patients and Information Directorate within NHS England, led by Tim Kelsey, a 'champion'. Participant has a 'complex role', involving 3 jobs.	Role; responsibilities; NHS England; Patients and Information Directorate
01:42	1.1	Legal framework in NHS England is different, as 'it doesn't stop at legal'. It also involves duty of confidentiality and also involves policy and guidance.	Legal framework; legislation
02:53	1.3	Recent organisational hierarchies 'should be available'. Difficulty in finding recent organisational hierarchies could be because the 'pace of change is so quick' in the NHS. Once a structure is 'nailed down', the NHS is experiencing yet another structural change. Participant recommends submitting a FOI request.	Organisational hierarchies; Patients and Information Directorate
[Recording failed due to battery. Summary taken from interview notes].	1.2	Qualifications include History and MA in Archives and Records Management at UCL. Participant has also worked in a number of organisations before an 'opportunity' at the NHS arose; previous organisations include Staffordshire County Council and the British Library.	Training; experience; background; MA Archives and Records Management
Track 2			
00:31	2.1	The NHS <i>RM Code</i> has 'not helped [...] as it isn't a Records Management code of practice'. The retention schedules have 'no logic'. 'For an organisation that is perpetually going through change they haven't grasped the concept that if we did things on a functional basis they would be consistent'.	NHS <i>RM Code</i> ; functional organisation

01:28	2.1	Distinction between clinical and corporate records makes Records Management issues more difficult. Corporate records are 'complex'. The code put Records Management 'on the agenda, which is good' but it 'assumes knowledge' from its audience. The code 'feels like a missed opportunity'.	Clinical records; corporate records; NHS <i>RM Code</i>
02:19	2.3	Some Records Managers would have been involved in the construction of the code, but they 'would not have lead the team'. Role of the Records Manager in the NHS is changing: 'There are a few professional Records Managers left in the NHS, they haven't got rid of all of them, many of them have ended up as IG professionals', with Records Management as just one responsibility in a wider role.	NHS <i>RM Code</i> ; Records Managers; IG
02:50	2.1	The NHS <i>RM Code</i> states that 'electronic patients' records should be kept forever, so the document itself is breaking the law'. The code is 'well-intentioned but I don't quite understand what it was trying to achieve'. The code ignores the archival perspective and also ignores appraisal.	NHS <i>RM Code</i> ; Data Protection; legislation
04:15	2.2	Open Data and Records Management are 'unfortunately different concepts'; Records Management is 'defensive', whereas Open Data is 'progressive'. The NHS is divided between 'innovation' and 'business-as-usual, and Records Management falls into business-as-usual. Nobody cares. Nobody will give it money and it only becomes an issue when it becomes a problem'.	Open Government Data; Records Management
05:26	2.3	Difficulty in answering how the Records Manager fits in with an Open Government Data agenda as the participant is 'not sure how many traditional Records Managers there are'. There has been a mutation into IG, as mentioned earlier. Open Data 'is not really on the radar' as people are 'not banging on the door about it'.	Records Management; Open Government Data

06:40	2.3	Transparency and Open Data may 'become business-as-usual, and at that point it becomes the Records Managers' problem'. Open Data is 'too new of a concept and is still something that is being chewed over', with many still asking the question, 'What does Open Data mean in health?'. Clinician and patient reactions to Open Data 'are not positive'; these two main producers of information would 'react adversely to Open Data'.	Transparency; Open Government Data; Records Managers
09:19	2.3	Some death rates from Clinicians will be 'incredibly high' as they take on the most complex of operations. This relates to the problem of interpretation: 'We can publish the data but we just don't know how people will interpret the data, creating a level of wariness'. There is a need for 'context, to stave off <i>Daily Mail</i> headlines and informs patients rather than scaring the life out of them'. Policy maturity of Open Government Data is 'not there yet' and the 'Records Management profession within the NHS is not visible or vocal enough to be involved in that kind of policy'.	Death statistics; interpretation of data; use of data by the media; Records Management
10:55	2.5	Open Government Data is 'best intentions at the minute'. 'DP is far more of an issue in the NHS. FOI is not done proactively'. There is 'not a natural synergy between FOI and Open Data'. Legislation can help to 'monitor compliance' and may increase financial investments. Open Government Data is on a 'piecemeal' basis currently. 'Lack of legislation increases the lack of clarity. If you are serious about the agenda, you are best pushing for more clarity'.	Open Government Data; FOI; legislation
14:37	2.7	'Nearest to an organisational policy you are going to get is [Head of Data Policy's work]'	Policies; organisational policy

15:53	2.4	IGT's self-assessment aspect 'good at telling you how wonderful you are' but limited at giving an indication of possible fines. IGT is supposed to include a second layer of monitoring from external auditing. IGT, if done properly, 'could be a useful tool' by mapping weaknesses and strengths and by showing risk. 'All they are measuring themselves on is whether they have passed the toolkit'. IGT and IG is 'about attitude'; both can be 'an engine for change and risk management'. Others, however, 'will always score themselves at 100% on the toolkit'.	IGT; benefits; barriers
22:27	2.11	Data Policy Unit 'absolutely plugged in to international practice', they understand the need for gaining 'expertise' from elsewhere.	International practice; influence
24:42	2.1	Head of Data Policy 'will always talk to people and listen to their opinions'. A space for Records Managers in Open Government Data would need to 'be actively carved out'. Records Management perceived as very narrow, 'relevance of expertise would not be seen'. Partnerships with others, such as the 'informatics team', could help. Records Managers are synonymous with 'filing clerks' and IG is perceived as meaning 'bad news, the people who generally say no, which isn't true'. 'It's like the guy who makes the coffee suddenly offering you an option on Albert Einstein's theory of relativity'. Records Management as part of the Open Government Data 'is not an easy sell'.	Records Management; Open Government Data
28:40	3.1	There should be metadata standards with the HSCIC, although the participant is not sure how far along they are with the development of the standards, but 'there is a logic there'.	Metadata; standards
29:30	3.2	In the NHS, 'there is always some form of management' and 'it will have gone through some prep[aration] before it has gone out'. This is because there are sometimes data quality issues with raw data.	Raw data
30:32	3.3	Participant is unsure whether a raw source is captured in the metadata of processed data, although 'logically there should be'.	Raw data; traceability

31:28	3.4	2018 paperless target is 'brave'. Organisations such as NHS 'are immensely transitory'; participant has experienced seven structural changes in six years. These changes 'do not encourage a corporate memory'.	Electronic records; clinical records; corporate records
33:58	3.5	In the NHS, 'the client is the patient' and this is seen in the <i>NHS Choices</i> website which serves the decision-making public. In the participant's view, [the Head of Data Policy] is 'socialising the organisation to the proper concept of Open Data and choosing things that ring bells, such as obesity'.	Users
36:15	3.8; 3.9	If Open Government Data is 'done properly' then there would be an 'informed public' who can 'scrutinise bad practice and support good practice'. Currently, 'we are not very good at it, or very confident at it, and we really need to educate it'. The participant considers reports seen in the <i>Daily Mail</i> and questions 'How do you expect this to work?'. Open Government Data 'could make you more transparent about processes and money'. 'The more open you are, the more nervous people get'. 'Is this really the best design? It may be the best we have come up with. I don't think anybody wants to have that debate'. Participant agrees that there is a gap between assumed and actual benefits in Open Government Data. Champions and key practitioners are leading the agenda, but they are only a minority who 'believe in the concept'. Link made to the practitioner who took over Dr Harold Shipman's centre, 'there is a need for transparency as a lot of public trust needs to be re-built'. Participant agrees that the Open Government Data in the NHS is fragile in the way that it relies on a few central figures to lead the agenda: 'NHS works on people not systems. You take the people out and it doesn't work'. Sometimes a person-dependent approach is 'necessary'. The interviewee has experienced such approaches elsewhere, although it didn't feel quite so 'person-dependent'.	Benefits; barriers
43:58	5.1	Open Government Data 'needs to be an accepted concept'. 'What do we think more data will do?'. There is a need to provide context to the data so that it is properly understood.	The future

47:17	5.2	<p>'Central Government wants scrutiny on local government, it doesn't want scrutiny on Central Government, so it's a political agenda'. Tony Blair's hostility to FOI is an example of this. 'It feels narrowly political'. It is 'nonsense' that FOI will become redundant. FOI gives you a 'legal right to request, regardless of whether you get the data'.</p>	<p>Legislation; FOI; The future</p>
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Thank you for taking part in this research. The central aim of this project is to consider the role of recordkeeping in the context of new obligations on the NHS sector towards Open Government, Open Data and enabling greater information access to citizens.

Please remember to sign the consent form.

Please type your responses below each separate question. If the question appears unclear, then you can ask for further clarification.

1. Role and Responsibilities

- 1.1 Please can you give an overview of your role within HSCIC and the responsibilities of the department within which you work?

My role is to support the HSCIC's Head of IG. This means providing mainly (but not exclusively) internal IG advice about the HSCIC's collection and dissemination of patient identifiable data.

- 1.2 Are there organisational hierarchies available for the HSCIC that demonstrate the position of the department within which you work in relation to the rest of the organisation?

I have not seen one during my 9 months at the HSCIC.

- 1.3 The HSCIC is described as 'an executive non-departmental public body'. Could you explain more about the HSCIC's relationship to Government and to NHS England?

The HSCIC was established under the Health and Social Care Act 2013. It took on the work of the former NHS Information Centre and part of the Dept. of Health (DH) known as 'Connecting for Health'.

The HSCIC is a body which is a legal entity in its own right and hence 'executive non-departmental public body'. This differs from say Public Health England who are an executive agency of the DH and not a separate legal entity. The HSCIC though is a 'creature of statute' with minimal discretion to act outside what is set out in legislation.

The HSCIC has a strictly defined relationship with DH and NHS England, set out in the Health and Social Care Act. Both organisations can issue formal legal 'Directions' instructing what data the HSCIC must collect.

- 1.4 Could you briefly explain a little about your professional background and qualifications?

After graduating I worked in sales and operational retail management before

joining the Information Commissioner's Office (ICO) in 2001 to manage one of the complaints teams. From that start I gained experience in DP and FOI and worked in complaints, policy, enforcement and stakeholder relations. I worked across the private, health, local government and police sectors.

In my final years at the ICO I worked closely on local govt. initiatives such as Troubled Families as well as providing expert advice to the NIGB and the HRA's Confidentiality Advisory Group.

My primary degree is a BA in History. I also have an MBA as well as and Data Protection ISEB qualification and an ISO9001 Lead Auditor qualification.

2. Policies

Publicly available policies, guidance and toolkits

- 2.1 The NHS Records Management Code is supported by material such as the Information Governance Toolkit. What are the benefits and barriers to the self-assessment aspect of this toolkit?

Benefits – it provides organisations with a mechanism to do what is required given their circumstances rather than a one size fits all approach. At the same time though the basic approach of the toolkit is applied to all NHS organisations thus ensuring a degree of consistency

Barriers – too often some organisations have found it relatively easy to 'game' toolkit completion and thus recording high toolkit scores which did not reflect the reality of IG practice within that organisation.

- 2.2 Another interviewee has commented that the Information Governance Toolkit is done without question in the NHS, despite not being mandated by legislation. Do you think there is anything in particular that forces compliance?

While there might be no specific legislation there are a number of drivers behind this. To begin with the idea of patient confidentiality is one that has been at the heart of the doctor patient relationship since time immemorial. More recently this concept has been supported by data protection legislation and in particular in the way it t[r]eats personal health data as especially sensitive. Finally in early 2008 as part of the Government's response to HMRC's loss of data on over a third of the UK's population, the then head of the NHS, Sir David Nicholson wrote an open letter to all health service bodies which basically mandated the reporting of all security breaches both centrally and to the ICO. This has now been developed so that all security breaches reported through the IG toolkit are now automatically sent to the ICO.

A further push comes from the way organisations now seek to establish IG toolkit scores before providing patient confidential data to other bodies. This can be seen in the way the HSCIC disseminates such data. Failure to provide adequate evidence of appropriate security measures including IG toolkit scores means that data will

not be provided to requestors.

All of the above helps to support the completion of the toolkit

- 2.3 The Open Government Data initiative is not currently underpinned by any legislation, in the way that FOI and DP is. Do you think this is an issue?

In short no. While there is no specific legislation, FOI covers a lot of this area. Most people are familiar with the legislation as a way of accessing official information by requesting it from public bodies. The legislation though also requires such bodies to proactively publish information through what are termed 'publication schemes'. This requirement does underpin this particular initiative.

Internal/organisational policies

- 2.4 What organisational policies are in place at HSCIC around Open Data and the publishing of health sector information for re-use by the HSCIC?

The HSCIC is mandated at s260 of the Health and Social Care Act to publish all the aggregated and anonymised data it receives under a Direction from the DH or NHS England.

- 2.5 How are these policies (or adherence to these policies) monitored?

I'm unsure if there is any pro-active monitoring of this.

- 2.6 Are these policies reviewed? If so, how and when? Who reviews these policies?

The policy is driven by legislation and I am not aware of any plans to review this in the near future.

- 2.7 Have Records Managers been involved in the construction and review of the policies and standards?

Yes – in particular in establishing an accurate register of all the information held by the HSCIC.

- 2.8 Does HSCIC look outward at international practice to help develop their policies? If so, can you give any examples?

Not that I am aware of.

- 2.9 What challenges have you experienced in relation to developing policies for the construction and management of Open Government Data at HSCIC?

The biggest problem is of a technical nature and that is ensuring that what the HSCIC publishes is as detailed as possible but without identifying any patients or even having the possibility of such identification.

3. Practice

3.1 Is there a standardised process for creating and applying metadata to Open Government Data at HSCIC?

This is not a question that I can answer.

3.2 Is it mostly raw data or mostly processed data that is published?

Processed because most raw data that we receive is patient identifiable and thus needs to be de-identified before publication.

3.3 If processed data is published, can you guarantee traceability back to the raw data?

In most cases yes, although in a lot of circumstances it will not be possible to go back to individual level data.

3.4 How specifically does HSCIC help 'health and care organisations improve the quality of the data they collect and send' to HSCIC?

The HSCIC will work closely with the organisations and the suppliers they use. Where problems are found in terms of the quality the HSCIC will help organisations to improve their data quality.

3.5 Who is the Open Government Data aimed at? Do you have an average user in mind when publishing Open Government Data?

No. It could be anyone from large corporate users to small but effective developers such as 'Openly local'.

3.6 How is it determined which data should be published? Who determines which data should be published?

See the answer to 2.4 above.

3.7 Are users and/or usage of Open Government Data monitored?

Not that I am aware of.

3.8 Attention has recently been given to the sharing of data at HSCIC. How do you think the reporting of such issues in the national media impacts the Open Government Data agenda?

I am not sure it impacts on this. What it does impact on is our ability to collect patient information in the first place. Already there are large numbers of people who do want their identifiable data used for anything other than their direct care.

3.9 What do you think are the benefits of publishing health sector information for re-use? Do you have any evidence of these benefits?

At the very least it improves transparency. In theory it might help improvements to the system by making data available which will clearly point to where improvements can be made.

I am aware of stories of some benefits but I have no evidence to hand at this time.

3.10 What do you think are the barriers to publishing data in the health sector for re-use? Do you have any evidence of these barriers?

I have no evidence of barriers to the publication of anonymised information.

4. Definitions

4.1 What do you think are the key formal elements, attributes, and nature of Open Government Data?

Publication of official data in a reusable form with straightforward availability. I cannot provide a more technical answer than this.

4.2 What do you think is meant by the word *Open*? Does it mean information should be open and useable/able to manipulate, or can it just mean that information should be open and readable?

Open and usable to manipulate as far as possible.

4.3 Do you think there is a difference between the terms *Open Government Data*, *Open Data* and *Open Government*?

Yes.

4.4 Open government data is often talked about alongside concepts such as *accountability* and *governance*. How would you explain the relationship between these different concepts?

I think it is more FOI that is about accountability. To me Open Government Data is about making official information available in a re-usable form for third parties to use in new ways to improve practices and services.

4.5 *Transparency* is inevitably mentioned alongside *Open Data* on the HSCIC website. Is this relationship between these two concepts specific to the NHS? Could you explain more about this relationship?

To answer the first part of your question I don't think so. As for the wider relationship between transparency and open data, as I said I think it is FOI which is

the key to transparency. Using FOI may result in open data being made available and which in turn may aid transparency but ultimately to me Open Data and Transparency while linked are separate concepts and should be seen as such.

5. The Future?

5.1 What are the plans for the future in terms of the management of open government data at HSCIC?

I am not aware of any specific plans.

5.2 How would you personally like to see open government data progress in the future?

To continue to make more data available in a re-usable form so that such an approach across the public sector becomes 'business as usual'.

5.3 What do you think to the suggestion by a Cabinet Minister that Open Data will replace FOI, making the latter 'redundant'?

As I said the two are separate but linked. One important point is that FOI gives an individual the right to ask about any information held by a public body. By contrast Open Data allows the public body to dictate what information it makes available. It is a crucial difference.

6. Plenary

6.1 Are there any other issues you think are important to raise concerning open government data in the health sector and at HSCIC?

Not at this point.

Thank you for your time.

Appendix E – Submitted FOI Request

Submitted FOI Request (via email) – Submitted 15 June 2015

Emma Harrison
Mon 15/06/2015 20:14
Sent Items

To whom it may concern,

My full name is Emma Harrison and I am making the following FOI request:

Could I please have a copy of the most recent structures of NHS England? Structures available on the websites do not reflect the most recent structural changes. I specifically would like to see an up-to-date organisational hierarchy for the Patient and Information Directorate, including the position of the Directorate within the wider NHS structure, and a hierarchical breakdown of the Directorate itself, including all positions.

I would also like to see the up-to-date organisational hierarchy for the Data Policy Unit, including the position of the Unit within the wider NHS structure, and a hierarchical breakdown of the Unit itself, including all positions.

Please could the response to the above request be sent to the following email address:
emma.harrison.14@ucl.ac.uk

I would like the information to be in a re-useable format, such as a Microsoft Word Document.

A timely response would be much appreciated.

Kind regards,
Emma Harrison

NHS FOI Response – Received 11 August 2015

Dear Ms Harrison,

Re: Freedom of Information request (Our Ref – FOI: 007715)

Thank you for your Freedom of Information (FOI) requests dated 15 June 2015.

Your request was:

“Could I please have a copy of the most recent structures of NHS England. Structures available on the websites do not reflect the most recent structural changes. I specifically would like to see an up-to-date organisational hierarchy for the Patient and Information Directorate, including the position of the Directorate within the wider NHS structure, and a hierarchical breakdown of the Directorate itself, including all positions. I would also like to see the up-to-date organisational hierarchy for the Data

Policy Unit, including the position of the Unit within the wider NHS structure, and a hierarchical breakdown of the Unit itself, including all positions.”

NHS England holds some information relevant to your request.

NHS England has interpreted your request to be for the Patients and Information structure chart. Please find attached the most recent Patients and Information structures. Information regarding the Data Policy Unit can be found on slide 7. Please note that this is correct as of 31 March 2015. If we have interpreted your request incorrectly please do not hesitate to contact us.

We would like to apologise for the length of time it has taken to provide you with a response to your FOI request. This fell short of our standards and I would like to offer our sincere apologies for the delay incurred.

I hope this information is helpful. However, if you are dissatisfied, you have the right to ask for an internal review by writing to us, within two months of the date of this letter.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner’s Office (ICO) can be contacted.

Please note there is no charge for making an appeal.

Please be aware that in line with the Information Commissioner’s directive on the disclosure of information under the FOI Act, your request will be anonymised and published on our website as part of our disclosure log.

Yours sincerely,

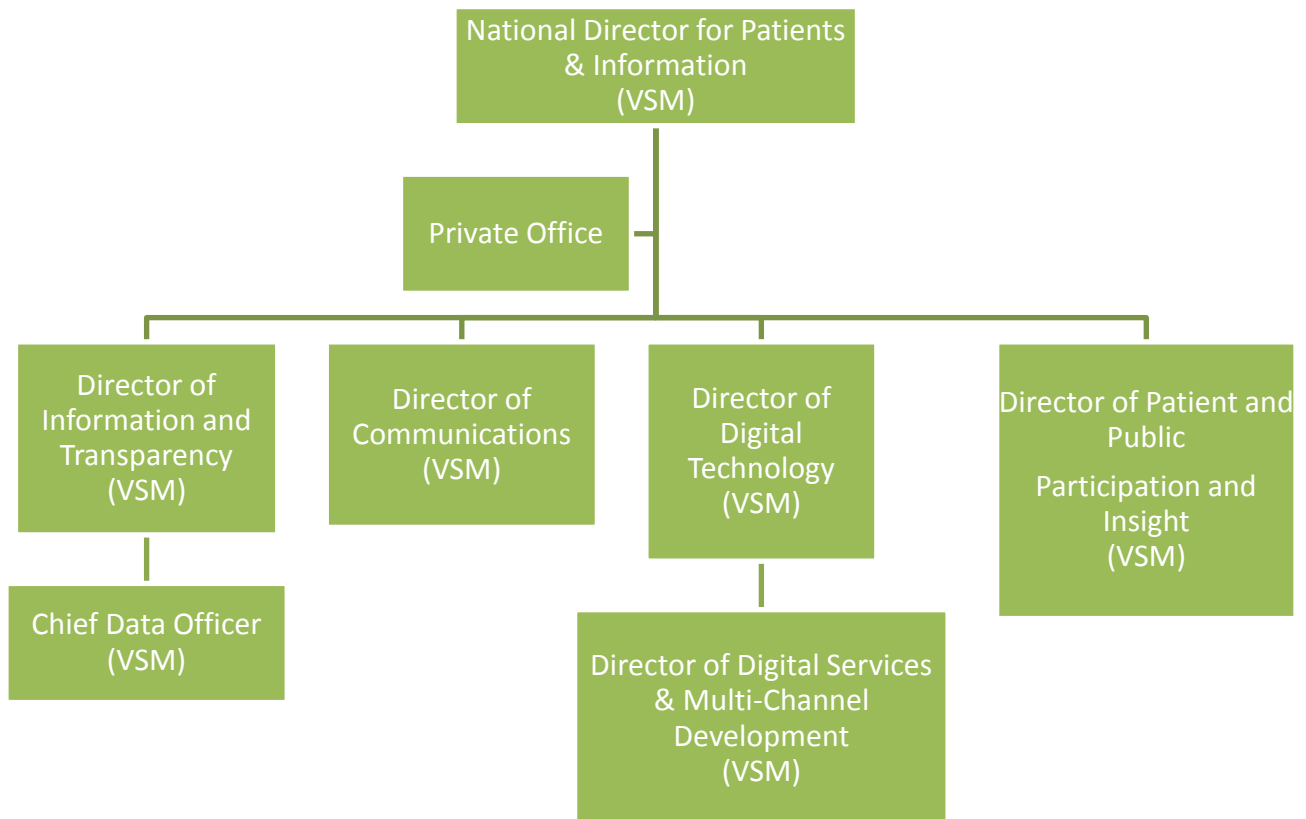
Freedom of Information

Corporate Communications Team

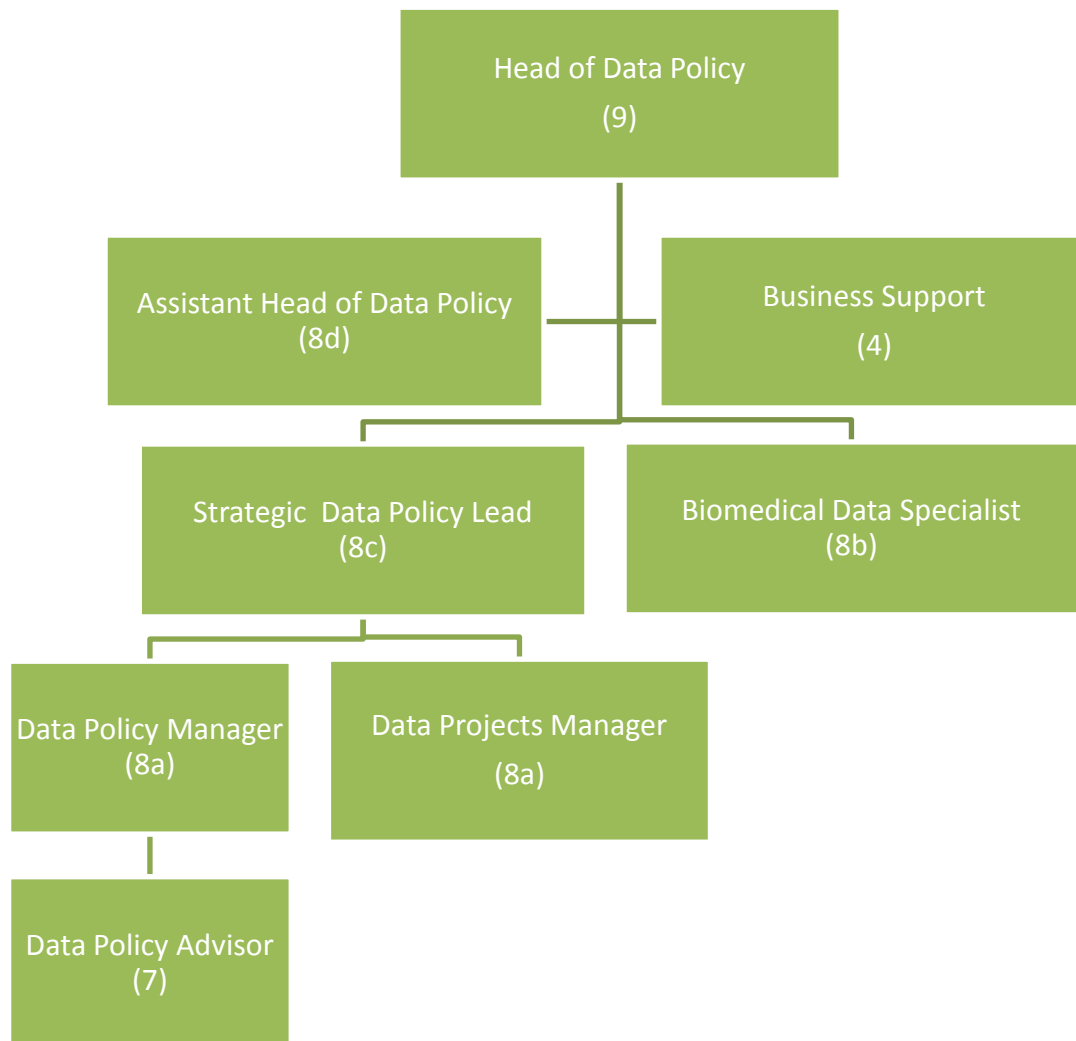
Patients and Information Directorate

[Organisational charts can be found on the following pages].

FUTURE **Patients & Information** **Senior Team (NSC)**



FUTURE
Patients & Information
Data Policy Unit



FUTURE
Patients & Information
Data Sharing and Privacy Unit

